DOCUMENT RESUME

ED 231 149 EC 152 589

AUTHOR Bauserman, Deborah; And Others
TITLE Autism in Virginia: A Statewide Study. Summary. [and] A Study of Statewide Services for Persons with Autism in Virginia. Final Report.
INSTITUTION School for Contemporary Education, Springfield, Va.
SPONS AGENCY Virginia State Dept. of Mental Health and Mental Retardation, Richmond. Developmental Disabilities Unit.
PUB DATE Sep 81
GRANT DD-79-16
NOTE 285p.; The study was also conducted by Grafton School, Berryville, Virginia.
PUB TYPE Reports - Evaluative/Feasibility (142) -- Reference Materials - Bibliographies (131)

EDRS PRICE MF01/PC12 Plus Postage.
DESCRIPTORS Annotated Bibliographies; *Autism; Definitions; Delivery Systems; Elementary Secondary Education; Facility Case Studies; Parent Attitudes; Residential Programs; *Special Education; *State Programs
IDENTIFIERS *Virginia

ABSTRACT

The two documents combined here both pertain to the same 18 month study of autism in the state of Virginia. "Autism in Virginia" is a six page summary of the 250 page final report; it is intended for parents and professionals needing to get at the highlights of the larger document. The final report presents detailed findings from a study of services for persons with autism in Virginia. A literature review section includes an annotated bibliography on 17 aspects, including history of autism, definition, assessment, etiology, education and treatment, family factors-parent involvement, adolescence and adulthood, model programs, and books for children. Each section includes a narrative summary and references for further reading in addition to the annotated listing. Data gathering involved developing a checklist for the definition of autism; surveying 118 parents or guardians; surveying public schools, and public and private institutions; and evaluating services based on site visits to 12 facilities. (Parent survey, autism checklist, and evaluation information are appended.) Among the findings were that: 98 percent of the persons described by their parents on the Autism Checklist were considered to be autistic; parents indicated primary needs for education and training in socialization, specifically in the use of leisure time; and that most available services reported by 41 facilities included education, training or treatment/growth services followed by identification, support, and family services. Specific recommendations were offered for identification and diagnostic services (including adoption of a state definition of autism); education, training, and treatment services; related support services (including establishment of mandatory levels of speech and language training); family services; employment services (including funding for followup); living services; and social, legal, and informational services (including use of a computerized management information system). (CL)

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ED231149

AUTISM IN VIRGINIA

A STATEWIDE STUDY

CONDUCTED BY

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Summary

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DEPARTMENT of MENTAL HEALTH & MENTAL RETARDATION
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EC152589

Printed by: The Sheltered Occupational Center of Northern Virginia

FOREWORD

In August, 1979, Grafton School in Berryville, Virginia, and the School for Contemporary Education in Springfield, Virginia, were awarded grant monies following a competitive request for proposals by the Developmental Disabilities Unit of the Virginia Department of Mental Health and Mental Retardation. The result of the one and one-half year study that ensued is now available as a 250 page monograph entitled A Study of Statewide Services for Persons with Autism in Virginia from

"Autism in Virginia"
School for Contemporary Education
7203 Wimsatt Road
Springfield, Virginia 22151
(703) 941-7704

The study is being disseminated under a separate grant to the School for Contemporary Education from the Developmental Disabilities Unit.

This paper represents a summary of the monograph and is designed for parents and professionals who desire information regarding the highlights of the original study. The authors hope that the study and the booklet together will stimulate action throughout Virginia by groups interested in the welfare of people with autism.

The opinions expressed within the report are based on the interpretations of the findings by the research staff and do not necessarily reflect the views of the granting agency.

INTRODUCTION

Providing services to people with autism is difficult for a number of reasons: 1.) long term care is frequently required due to the severity of the handicap, 2.) needed treatment is not available from existing agencies, and 3.) autism is a rare condition. However, many agencies within Virginia, such as the Department of Mental Health and Mental Retardation, Health, Welfare, and the Division of Vocational Rehabilitation are required to provide services to people with severe handicaps such as autism. Further, state and federal laws require the education of all children between the ages of 2 through 21. As a result, The Commonwealth of Virginia is in the process of planning improved services for people with autism.

The Nature of Autism

Description and Definition

The best known modern description of autism was made in 1943 by Leo Kanner. The traits of autism described by Kanner began in infancy and included an inability to develop relationships with people, serious speech and language problems, unusual play activities, an obsessive desire for sameness, a lack of imagination, and a good rote memory. The children Kanner observed all appeared to have normal physical appearance. After the age of 6, many children improved. A large percentage of people with autism are also mentally retarded and have other handicapping conditions such as epilepsy, and deafness.

The definitions of autism which seem to be most widely in use today include a definition written by Ritvo and Freeman in 1977 for the National Society for Autistic Children (NSAC) and the definition found in the third edition of the Diagnostic and Statistical Manual (DSM III).

The NSAC definition specifies the following as essential characteristics:

1. manifested before 30 months of age
2. disturbed developmental rates and sequences of growth
3. disturbed responses to sensory stimuli
4. disturbed speech, language and cognitive capabilities
5. disturbed capabilities to relate to people events, and objects

Assessment

An accurate, comprehensive assessment should be conducted by a team of specialists in order to determine if a person does have autism. The team should include a licensed psychologist, a certified speech specialist, an educational diagnostician, parents, and a doctor. Assessment techniques used should include observation of the person with autism, parent interview, and informal testing procedures. The purpose of assessment is to determine the person's level of mental development, language ability, behavioral patterns and motivation. The Annotated Bibliography contained in A Study of Statewide Services for Persons with Autism includes a descriptive list of assessment instruments.

Cause of Autism

The notion that parents of persons with autism are responsible for the handicap due to their own emotional difficulties is no longer believed. The causes of autism are still unknown, although research suggests that several causes may be involved. There is strong evidence that autism has biological or physical causes such as impairment of the brain.

Prevalence

Autism is a rare condition. Studies conducted in the United States, Denmark, and England suggest that there are probably 2 to 5 persons with autism in a population of 10,000 persons. A generally accepted figure for estimating the number of "classic" autistic persons is 3 to 4 per 10,000. However, some experts believe that if people with autistic-like characteristics are included (since they require similar education and treatment), there are 10 to 20 per 10,000. The Virginia study used the figure of 15 per 10,000 for estimating service needs.

Diagnosis

There has been much confusion in accurately diagnosing autism. Many problems can be created for the person with autism if the condition is not accurately diagnosed. Unfortunately, in many parts of the country it is still very difficult to find someone who knows about autism. Also, several factors create difficulty in diagnosing autism:

1.) Enormous variations in severity occur. Autism can be very mild or severely incapacitating.

2.) Autism is almost always accompanied by additional handicaps. Persons with autism may be deaf, blind, and have problems with motor function, or seizure activity. Approximately 70 to 80% are mentally retarded.

3.) The characteristics of persons with autism change as they grow older.

4.) There are differences between girls and boys in the frequence and severity of autism.

5.) The environment affects the behavior of the person with autism.

Education and Treatment

Special schooling for autistic children is associated with academic and social benefits. The behavior modification approach to teaching autistic children is, to date, the most widely used approach. This approach involves reward of appropriate behaviors and ignoring or punishing inappropriate behaviors in a systematic and consistent manner. The learning environment should be consistent, routine and structured. The content areas that are essential in a curriculum are self-help, language, social, motor, academic, pre-vocational and vocational skills.

Family Factors

Parents have always been thought to play an important role in the lives of their autistic children. Unfortunately, in the beginning parents were thought to have caused the autism by being "cold and aloof", "unemotional", and "refrigerator parents". One well known writer recommended that the child be removed from the parents for treatment. Schopler called this "parentectomy" practice "scapegoating" by professionals.

Today, most professionals advocate parental involvement in all aspects of the treatment program. Children whose parents were trained to carry out behavior therapy continued to improve after discharge while children in institutions with untrained parents became worse. When parents and professionals work together, both can benefit from the relationship.

Adolescence and Adulthood

There is an obvious lack of services for adolescents and adults with autism. Persons with autism have a normal life span, so the majority need services for all of their lives. A study showed that in adulthood, only 5 to 15% of people with autism obtain a "good" outcome. Few lived independently with 50 to 80% at home or institutionalized. While about 50% developed language, many had developed neurological problems, and only about 5% have employment. Group homes seem to represent an important treatment alternative for older persons with autism, although few are currently in existence.

METHODS

The methods used to study services to people with autism in Virginia were complex and varied. Briefly, instruments were developed as tools in the study and included an Autism Checklist so that parents could describe their child with autism, a Parent Survey which asked many detailed questions about their child, a Descriptive Survey which was sent to many agencies in the state to determine the type of services available and the types of persons served, and an Evaluation of a small number of service agencies. Results were computer analyzed.

RESULTS AND DISCUSSION

Recommended Definition of Autism

Using the NSAC definition as a guide, 98% of the persons described by their parents on the Autism Checklist were found to be autistic. Futher, 93% of the children so studied had also been independently diagnosed at one time or another as autistic or autistic-like. These results lend credibility to other findings in the study. These results also support the recommendation that the NSAC definition should be adopted in the Commonwealth of Virginia to identify other persons with autism.

The Number of Persons with Autism

The study identified only about 4% of the expected population of people with autism in Virginia. Those identified are also expected to be receiving the best services available in the state.

The age of the persons counted were as follows:

Age Category	Expected Autistic	Identified Autistic	Percentage of Expected
0 - 5	806	35	4.3%
6 - 12	1,101	150	13.6%
13 - 21	1,363	92	6.7%
21+	4,526	33	0.7%

As it can be seen, a higher percent of the school aged population has been identified than the non-school-age population.

The functioning levels of the identified persons with autism were studied and found to be as follows:

Intelligence (IQ)	-The majority of persons have IQs below 50. Only 18% have IQs above 70.
Self-care	-Most persons are able to independently feed, dress, and toilet themselves.
Social	-Most are unable to use toys or materials appropriately or to join in group activities.
Behavior	-Most of the persons show intermittent or mildly bizarre or destructive behavior.
Communication	-Half of the persons are able to communicate basic needs. Only 15% can carry on a conversation.

It was found that agency ratings were lower than parent ratings, although both parents and agencies rated the persons with autism as low functioning which indicates the severity of the handicap.

Description of Services Currently Available in Virginia

Parent Responses

Most of the parents responding have children who are 6 to 12 years old. The parents indicated that the current services needed by their children are those that would improve social and vocational skills. Also, many parents stated a need for skills to help the family to help the handicapped family member. Regarding future service needs, almost every service possible was requested. The most frequently noted future needs included education and training and socialization (such as how to use leisure time, community resources, interact with peers), prevocational and vocational instruction, and support

services (transportation, recreation, speech and language training). Parents were also asked about their level of satisfaction with current services and many positive responses were made. However, parents expressed lack of satisfaction with certain education, language, socialization and vocational programs. Also, family services were seen as deficient. If the respondents represent the best served people in the state, what needs exist for those currently not even identified?

Agency Responses

The total number of students recognized by the school divisions as having characteristics similar to those of autism is 217 - only 2% of those expected to be in public schools! Thus, relatively few local school divisions report providing services for the autistic or autistic-like student. Also, only one-third of the divisions are serving children recognized as having characteristics of autism.

In ten state institutions, 63 persons with autism were reported, most of whom are lower functioning in relation to others in the state. Five private, non-profit facilities report serving a total of 51 persons with autism. Most of these are designed for mentally retarded persons.

Overall, it was found that there is not a comprehensive, integrated system of services for the autistic person. No state agency has clear responsibility for this population. The State Department of Education does not recognize autism as a distinct disability and therefore has no program guidelines, no teacher endorsement, encourages no teacher training in higher education, and has no funding reimbursement formula for local school divisions for the disability of autism. It is not surprising that few local school divisions can provide adequate services for this population. The State Department of Mental Health and Mental Retardation provides services in isolated, non-integrated residential settings for only a minimal number of persons and these services are designed for the severely intellectually impaired. Only a few facilities in Virginia's relatively large private sector have begun to develop extensive services for this multiply impaired, difficult-to-serve population.

Services Currently Provided

The services provided are discussed in terms of a number of persons potentially receiving the services as determined by both the Parent Survey and the Descriptive Survey. Most typically, persons served are receiving some kind of education or training and related support services. The focus is on socialization, language training and personal independence skills. The least offered services are vocational and prevocational training. With regard to support services offered, most services are involved with communication with the family while little is being done for respite care or family counseling. Very few living (residential) or employment services are available in the state.

Evaluation of Existing Services

On site evaluations were conducted at a total of twelve different facilities, those serving more than 3 persons with autism. The evaluation of services was made by agency personnel in response to a structured format. The responses of parents on the Parent Survey were also taken into consideration. The results that are reported are focused on the services that need improvement, are not fully implemented and are critical to meet

the needs of persons with autism. The indirect services that require improvement include the writing of annual plans and short term objectives, components of the individualized education plan (IEP). The greatest number of high priority needs are found in the area of education and training, specifically for services in language, socialization, independence, use of the community and behavior management. Respite care services for the family and child day care were also reported as requiring high priority attention.

Overall, all sources of data support the need for providing persons with autism skills leading to independence. There are current needs for the development of services that promote social, vocational and independent living skills. Services to assist the family are also crucial. The occasional need for parents to be able to have temporary "leaves of absence" from their autistic family member is recognized.

RECOMMENDATIONS

Recommendations are made on the basis of the different service categories. Briefly, these are as follows:

Identification and Diagnostic Services

The General Assembly should adopt a state definition based on the definition adopted by the National Society for Autistic Children. Diagnostic centers should be accessible across the state.

Education, Training, and Treatment Services

The Virginia Overall Advisory Committee on the Needs of the Handicapped should establish a subcommittee to assure coordination of services across the state. Emphasis should be given by the General Assembly and the Department of Education for the funding of model programs and training for teachers.

Related Support Services

Guidelines should be established for mandatory levels of speech and language training, for coordination of school and home programs.

Family Services

The Overall Advisory Committee should appoint a subcommittee which would serve as an advocate for services to autistic persons and their families.

Employment Services

A state department should be designated by the Secretary of Human Resources in coordination with the Secretary of Education to provide training, counseling and job placement to persons with autism. Funds should be made available for on-the-job supervision and follow-up on job placements.

Living Services

The Overall Committee should designate a specific department to plan and to develop living services as an alternative to institutionalization. Also, study should be made of a "family subsidy" program so that families could purchase services for use within the home.

Social, Legal, and Informational Services

Use should be made of a computerized management information system. Also service directories should be made available.

A STUDY OF STATEWIDE SERVICES FOR PERSONS WITH AUTISM IN VIRGINIA

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Lori DeZarn, M.A.
S. Gail Mayfield
Grafton School

David L. Williams, Ph.D
School for Contemporary Education

Developmental Disabilities Unit Grant #79-16

EC 152 589

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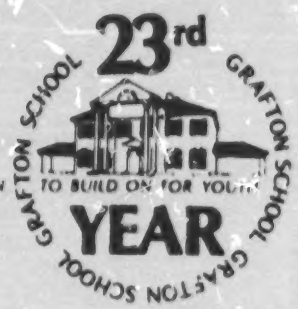
National Association of Private Schools for Exceptional Children (NAPSEC)

LETTER OF TRANSMITTAL



April 28, 1981

Ms. Linda Veldheer, Acting Director
Developmental Disabilities Unit
Department of Mental Health /Mental Retardation
109 Governor Street
Richmond, Virginia 23214

Dear Linda,

It is my pleasure to submit to you, on the behalf of the research staff, the final report of a study completed under the sponsorship of the Developmental Disabilities Unit, "A Study of Statewide Services for Persons with Autism in Virginia."

As you know, the study represents an enormous undertaking that involved hundreds of parents and professionals across the state, a clear demonstration of the enthusiasm and readiness that exists to begin work on the improvement of our state system of services.

At this time also I would like to thank you for your many generous and intelligent contributions throughout the project.

Sincerely,

Deborah N. Bauserman, Ed.D
Project Director

GRAFTON SCHOOL
Box 469
Berryville, Va. 22611
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LEO E. KIRVEN, JR., M.D.
COMMISSIONER

COMMONWEALTH of VIRGINIA

Department of
Mental Health and Mental Retardation

MAILING ADDRESS
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June 15, 1981

Robert W. Steig, Jr.
Headmaster
Grafton School
Box 469
Berryville, Virginia 22611

David Williams, Ph.D.
Development Director
School for Contemporary Education
7201 Wimsatt Road
Springfield, Virginia 22151

Gentlemen:

On behalf of the Department of Mental Health and Mental Retardation, we would like to recognize receipt of the final report of the Statewide Autism Study which was funded and administered under DD Grant #79-16. This report is accepted for review and study, as appropriate, by the various divisions, task forces, and committees within the Department which have interest in this topic. The final report of the study will be formally presented to State Mental Health and Mental Retardation Board members at their meeting on June 24, 1981. The DD Unit also will continue to work with you to develop mechanisms for the dissemination of this report, which has generated much interest among service providers and consumers.

In addition, we would like to commend you and the project staff for your tremendous expertise and commitment in completing this considerable task. It is hoped that this effort will produce positive outcomes for autistic individuals and the agencies which serve them.

Sincerely yours,

Leo E. Kirven, Jr., M.D.
Commissioner

C. W. Brett, Ph.D.
Deputy Commissioner

Linda C. Veldheer
Director, Developmental Disabilities Unit

LEK,Jr./CWB/LCV/m

FOREWORD

On August 8, 1979, Grafton School in Berryville, Virginia, and the School for Contemporary Education in Springfield, Virginia, were awarded grant monies following a competitive request for proposals by the Developmental Disabilities Unit of the Virginia Department of Mental Health and Mental Retardation. The result of the one and one-half year study that ensued is the subject of this report. The authors hope that the study will serve as a useful tool for the stimulation of concerted action throughout Virginia by legislators, professionals and parents who are interested in the welfare of people with autism.

The opinions expressed within the report are based on the interpretation of findings by the research staff and do not necessarily reflect the views of the granting agency.

The study is being disseminated under a separate grant to the School for Contemporary Education from the Developmental Disabilities Unit.

ACKNOWLEDGEMENTS

Grateful thanks are extended to the Developmental Disabilities Unit of the Department of Mental Health and Mental Retardation for providing the opportunity to conduct the study.

Special thanks are extended to the members of the Advisory Committee for their important contributions to the study:

Donald Biskin, Ph.D
Irene Bolton
Charline Davidson
Mike Etkin, Ph.D
Dave Fitch, Ph.D
Pat Juhrs
Lee Marcus, Ph.D
Anne Murphy
Ruth Page
Michael Rutter, M.D.
Carolyn Shenton
Phyllis Simmons
Linda Veldheer
Lew Ziske

For their long hours of patient work in case management and computer consultation involved in the statistical analysis of the results, the efforts of Phil Horvath, Al Watts, and Mike Etkin are gratefully acknowledged.

The opportunity to review the draft Report to the Secretary for Human Resources from the Committee on the Needs of and Responsibilities for Emotionally Disturbed Children (January, 1981) was appreciated. This Report addresses many of the same issues as the Autism Study, but for a different population, and the two studies offer complementary information.

Special appreciation is extended to Don Oswald for his behind-the-scenes assistance during the Advisory Committee Conferences and his reactions to the manuscript.

Special thanks go to the Board of Directors of Grafton School which made supplemental funds available to complete this study at a level the staff considered optimal.

Thanks also go to the members of the Grafton School and School for Contemporary Education staff who served in the capacity of providing assistance in follow-up and site visit activities and, finally, to Robert Stieg, Headmaster of Grafton, for his generous input at all stages of the project.

ABSTRACT

The service needs of persons with autism in Virginia were addressed through the completion of six major objectives: a literature review, a recommended definition of autism, an enumeration and description of persons with autism, a description of services currently available, an evaluation of services, and recommendations for the future service delivery system. The literature review culminated in an annotated bibliography suitable for independent dissemination as well as a review of other state studies or plans on services to the autistic. Based on the outcome of diverse procedures, a checklist for a definition of autism was proposed, drawing heavily upon the NSAC definition. The enumeration and description of persons with autism was achieved by a parent survey completed by 118 parents or guardians. Surveys sent to public schools, public institutions and private facilities resulted in descriptions of services currently available in 41 facilities in Virginia. Indepth evaluations based on site visits to twelve facilities offering advertized services to persons were also completed. Results obtained in the foregoing sections revealed a paucity of needed services in all areas and led to the following major recommendations that:

1.) the General Assembly pass legislation adopting a state definition of autism while the State Department of Education and the localities work together to make provisions for accessible diagnostic centers in each region of Virginia;

2.) the State Department of Education and localities work together to provide classes specifically designed for school-aged persons with autism either within the local school system or within the region;

3.) the Departments of Mental Health and Mental Retardation, Social Services, and Education coordinate their efforts to design and encourage existing services to provide training and respite care for families of persons with autism;

4.) a state department be designated by the Secretary of Human Resources in coordination with the Secretary of Education as having the lead responsibility for providing training, counseling, and job placement to persons with autism;

5.) to provide appropriate living services, the Commonwealth of Virginia must develop a continuum of living services that will lead persons to the least restrictive environment.

I. INTRODUCTION

In words that are as compelling today as when they were first written, internationally known researchers Lorna and J. K. Wing wrote that the provision of services to autistic persons is problematic for at least several reasons. 1.) long-term care for a large percentage of autistic persons is indicated due to the severity of the handicapping condition, 2.) the treatment of autistic persons cannot be neatly fitted into existing adminstrative categories of mental retardation or mental or physical illness, and 3.) autism is not a common condition (Wing & Wing, 1976). At the same time, passage of Virginia's Special Education mandate in 1972 and of the federal Education of All Handicapped Children's Act in 1975, have required that a free and appropriate public education be guaranteed by the State Board of Education for all handicapped children in Virginia aged 2 through 21. It is, further, the mandate of the Department of Mental Health and Mental Retardation to provide services to Virginia citizens who are more severely handicapped, more dysfunctional, and more dependent than the general population. Other state departments, such as Health, Welfare, and agencies such as the Division of Vocational Rehabilitation, also have mandates to assist in the identification, diagnosis, care and training of handicapped persons who meet their eligibility criteria. Thus, the combination of the unique, urgent needs of persons with autism and legislative as well as administrative prescriptions for responsive service has created the present challenge for the formulation of a comprehensive, statewide inter-agency plan for the provision of services to persons with autism.

The Nature of Autism

Description and Definition

Awareness of the handicapping condition we know as autism has been well-documented in the medical and psychiatric literature beginning with the study of feral children in the neneteenth century including Kaspar Hauser and Victor, the "wild boy" of Aveyron, who have frequently been cited as historically relevant to the understanding of autism (Lane, 1976; Simon, 1978). The most influential modern description of the syndrome is provided by Leo Kanner (1943) who coined the term "early infantile autism". He summarized the case histories of eleven children, abstracting from their behavior a number of features that seemed unusual in relation to other conditions such as schizophrenia and mental retardation as well as those which were characterized solely of the eleven children. The traits of autism described by Kanner, evident in infancy, included an inability to develop relationships with people, a delay in speech acquisition, noncommunicative use of speech, pronominal reversal, repetitive and stereotyped play activities, obsessive insistence on the maintenance of sameness, a lack of imagination, and a good rote memory. The children Kanner observed all appeared to have normal physical appearance. After the age of 6, the course of the condition was towards improvement, although the children remained severely handicapped. Kanner's original view regarding the innate nature of the condition, its distinction from other childhood

psychiatric disorders, and its progression towards improvement has largely been substantiated (Wing, 1976).

Although more people with autism are being identified and research in autism has increased dramatically in recent years, the nature of autism remains a subject of considerable confusion and disagreement. This confusion has led to errors in sample selection, needless frustration among clinicians and investigators, and unnecessary misinterpretations of important research (Schopler, 1978). Schopler suggests that confusion in the diagnosis of autism can be traced to at least three sources; 1.) inexperience in diagnosis or lack of scholary rigor, 2.) the complexity of the autism concept, and 3.) the differing purposes for classification.

Problems in Diagnosis. A definitive diagnosis of autism has been hampered by two problems, the choice of the name "autism" and the tendency to reduce and simplify the diagnostic criteria. With regard to the former, the use of the label "autism" immediately led to confusion with Bleuler's use of the same term to refer to the active withdrawal into fantasy shown by schizophrenic patients. The problems with the term autism were several: first, it suggested a withdrawal from relationships, whereas Kanner had actually described a failure to develop relationships, second, it implied a rich fantasy life, whereas Kanner's observations suggested a lack of imagination; and third, it postulated a link with schizophrenia in adults (Bosch, 1980; Rutter, 1978; Wing, 1976). The confusion was further compounded by a tendency among child psychiatrists to use childhood schizophrenia, autism and child psychosis as interchangeable diagnoses (Laufer & Gair, 1969).

Many additional difficulties with diagnosis have followed from Eisenberg and Kanner's (1956) reduction of the essential symptoms to just two, "extreme aloneness", and "preoccupation with the preservation of sameness" together with an onset in the first two years (Rutter, 1978). Subsequently, other writers have in turn selected varying features of autism for emphasis, resulting in varying sets of diagnostic criteria (Orintz & Ritvo, 1968; Rendle-Short, 1969; Schain & Yannet, 1960; Tinbergen & Tinbergen, 1972). Thus, to ask "How should autism be defined?" may distort the process of scientific enquiry; Popper (1959; 1972) has argued that the question is not "What is autism?" but rather "To what set of phenomena shall we apply the term autism"? Viewed in this light, Kanner's term "autism" must be regarded as more than a simple label, for it also suggests the hypothesis that behind the behavioral description lays a disease entity.

Complexity of the Concept. The complexity of the autism concept has also contributed to confusion in diagnosis. For example, according to Rutter (1978), the observation that autism can appear after apparently normal development in the first one to two years of life created an increasing tendency to ignore the age of onset as a necessary criterion for diagnosis (e.g. Creak, 1961) with the result that disorders beginning in early infancy were grouped together with psychoses not emerging until later childhood or adolescence (e.g. Bender, 1947; Vrono, 1974).

Further variables that affect the complexity of the condition include disparate etiologies, differing treatment needs, a wide range of cultures, intellectual levels, socioeconomic levels, and ocassional coinciding handicapping conditions (such as epilepsy, deafness and mental retardation).

Differing Purposes for Classification. The final point of confusion in the term autism, that is, the differing purposes for classification, has been described by Schopler (1978). He contrasts two important definitions, the first written by Rutter and the second written by Ritvo and Freeman for the National Society for Autistic Children (NSAC). He notes that Rutter's definition evolved out of the understanding of the syndrome from a historical and scientific perspective, whereas the NSAC definition arose for different purposes, namely, to help the group meet its objective of political and social action that would result in the education and treatment of persons with characteristics of autism.

Current Definitions. The term "autism" is currently used two ways: 1.) as the name of a hypothetical disease entity that underlies the symptomatology of the autism syndrome, and 2.) as a label signifying a unique cluster of deviant behaviors (or syndrome) that can be differentiated from other developmental disabilities. No definitive information is available to date to prove which biological factors might be the basis of autism as a disease entity although neurological factors are a prime suspect (Cohen and Young, 1978; Rimland, 1974; Rutter, 1970; 1978; Tanguay, 1976). Data gathered in the last decade, strongly indicates that parental attitudes toward and interactions with infants are not the cause of autism. Thus, the differing definitions of autism as a developmental disability share common themes but differ in terminology and emphasis (Field & Cohen, 1981). The resolution of differences among definitions of autism will depend upon the findings of professionals, who are still collecting and analyzing new data.

Prevalence

Equally as problematic as the issue of definition is the issue of the prevalence of people with autism. In an early study, Lotter studied the total population of 78,000 children aged 8, 9 or 10 in the county of Middlesex, England (1966). Cases of possible early infantile autism were identified and suggested a prevalence of 4.5 per 10,000. A later study by Brask in Denmark using a population of children between the ages of two and fourteen and a similar definition resulted in the same ratio (1979). Treffert (1970) examined the case records of all children, aged 12 and under, seen for evaluation and treatment in Wisconsin facilities, and reported a prevalence of 3.1 per 10,000. He did not screen a total population like Lotter or a population of children known to be handicapped as did Brask which may account for the lower prevalence figure. More recently, Wing and Gould (1979) completed a study utilizing a much broader definition of autism which yielded a prevalence of 20.1 per 10,000; the population studied included all children under age 15 whose parents lived in Camberswell, England and who had come to the attention of medical, social or educational services because of developmental or behavioral aberrations. In recent years the practice has evolved to employ a narrow

definition and smaller prevalence figure (5 per 10,000) when precision is required in studies of such questions as the cause of autism or the effects of education or training of persons with autism. However, when study is concerned with the planning of a broad range of services for an entire population of persons with autism or characteristics of autism, the accepted approach of such organizations as the National Society for Autistic Children and the Department of Health, Education, and Welfare is to use a broad definition of autism and larger prevalence figure for example, (10-20 per 10,000). Clearly, different decisions regarding choice of definition and prevalence of autism result in differing outcomes, outcomes that significantly influence interpretations of results.

Plan of the Study

The task of studying and recommending services for persons with autism in Virginia as requested by the Developmental Disabilities Unit of the Department of Mental Health and Mental Retardation represented a challenging undertaking. See Appendix A for the "Request for a Proposal". Each area of study has been the subject of rapidly increasing attention, controversy and debate. Almost as soon as questions are answered, new questions are posed. A critical requirement of the study was, therefore, to determine a plan which would best serve the objectives of the present study. Thus, in organizing a viable approach to a study of this magnitude, the principal investigators articulated a philosophical stance which incorporated three major principles. These principles were to begin with a clear set of priorities, to encourage consumer involvement, and to use existing state and local resources already available for handicapped persons.

Priorities

Regarding the first principle, a central priority of the present study was to emphasize enumeration of persons with autism, description of existing services and program evaluation in order to create realistic recommendations for an optimal future service delivery system. This stance seemed appropriate and reasonable when one considers the wealth of theoretical information already available as well as the fact that several states, notably California, South Carolina and North Carolina (Lansing & Schopler, 1976; Marcus, 1977) have already developed models for statewide service systems. The pressing need within Virginia is for a practical service model based on the unique characteristics of its citizenry and resources and which at the same time fulfills legislative mandates. The first priority, therefore, argued persuasively for the development of an applied service model as an outcome of clinical and statistical methodology.

Consumer/Provider Involvement

A second principle in the present study was to maximize consumer/provider involvement. In recent years, in response to the difficulties of program planning and evaluation, new emphasis has been accorded to studies of consumer satisfaction, a new emphasis which represents a

shift away from the attitude that the professional "knows best" (Hart & Barrett, 1975). The conclusion of many current researchers is that parents are not "frills" but integral members of a team in the habilitation and education of autistic persons (Kaufman, Bakalon, Tyson & Paredise, 1978). Parents of handicapped children, in addition, have made a significant impact on legislation through organizations such as the Association for Retarded Citizens, the Association for Children with Learning Disabilities and the National Society for Autistic Children (NSAC) as well as through assisting in child find programs. Teachers, administrators, specialists and ancillary personnel were invited to be involved in the present study in recognition of their unique experience in the delivery of services as well as their own needs for resources and training to maintain and improve those services. It is believed that if the effectiveness of a service delivery system depends in part upon the acceptance of services, then the interests, expectations and objectives of both consumers and providers take on new importance. Consumers and providers, some of whom were study participants designated as the Advisory Committee, were involved in all stages of the study, but particularly in defining the needs and assisting in the development of recommendations for the state plan. See Appendix B which describes the Advisory Committee.

State and Local Resources

The final principle underlying the present study was to use existing resources whenever possible. Due to the severity of the handicap in most persons with autism, one can assume that many are receiving some kind of service, although such services may be inappropriate for a percentage of persons. For example, many persons labeled as autistic are known to be currently receiving services in facilities that do not offer services specifically designed or advertised for the training and education of persons with autism. Indeed, the capacity of advertised programs for persons with autism is extremely small. It is unknown, further, to what extent existing programs are sufficient and appropriate in terms of services available, treatment strategies, geographical accessiblility, and number. The lack of services for persons with autism under the age of five and over the age of 21 is especially critical (Callias, 1978). It is believed, however, that the gaps in the present system do not need to imply that the system is irrevocably ill equipped to successfully serve persons with autism. A state structure is in place to serve the handicapped in Virginia; it is time to call attention to a small but important group of people who have, to this date, not received their share of resources and services.

Summary

Clearly, definition and research methodology affect our understanding about how many persons with autism may be found in Virginia. The prevalence of persons with autism, for example, must be given serious consideration since the establishment of successful training programs and the provision of services are predicated on an accurate assessment of the number of citizens to be served. Thus, the first step toward a systematic and comprehensive response from state agencies is the recommendation of an acceptable definition of autism, followed by enumeration of persons with

autism in Virginia. Related steps include systematic study of present services and projected service needs together with a careful evaluation of existing public and private resources within the Commonwealth.

II. LITERATURE REVIEW

The purpose of the literature review in the present study is two-fold: 1.) to provide an annotated bibliography which will be a resource to those interested in acquiring an overview on the subject of autism and 2.) to describe the studies completed by other states that have recently planned and implemented their own statewide service plans for persons with autism.

Annotated Bibliography

In order to enable readers to concentrate on specific areas of interest, the literature has been summarized in an annotated bibliography organized by subject areas. See Appendix C for the annotated bibliography.

The literature on autism has been extensive since the 1940's when the syndrome was identified by Leo Kanner. Because there was no clear definition of the syndrome for many years, the early literature can be found in various journals, magazines and books. A number of approaches were used to obtain the most comprehensive and useful entries for the annotated bibiography. Computer searches were conducted through the University of Virginia library; also, the Information and Referral Service at NSAC was utilized to obtain more recent publications. Finally, letters were sent to universities that offer course work in autism and to the directors of well-known "model" programs to request further information.

The categories selected for review within each section include the following:

1. History of Autism
2. Definition
3. Prevalence
4. Diagnosis - Symptomatology
5. Assessment
6. Etiology
7. Education and Treatment
8. Communication
9. Sign Language Texts
10. Family Factors - Parent Involvement
11. Adolescence and Adulthood
12. Major Texts on Autism
13. Books for Children
14. Model Programs
15. Virginia Service Directory
16. Virginia Society for Autistic Children
17. Sources of Information about Autism

There are three sections under each heading. First, each section has a brief narrative summary of the literature in that topic area. Second, there is an alphabetized list of annotated articles considered the most important and relevant in the section to provide a concise representation of the written literature in that particular subject area. Finally, additional references, not annotated, are listed for those interested in further reading in that topic area.

Additional copies of the annotated bibliography as a separate reference are available from the National Society for Autistic Children (Washington, D.C.).

State Studies and Plans for Services to the Autistic

The gathering momentum brought about by the forces of new legislation, developing parent and advocacy groups, contemporary research and educational technologies has created an upsurge in efforts by state planning committees to study the needs and plan for more comprehensive services for persons with autism. North Carolina led the country in providing such services, but in recent years, ten additional states[1] have followed suit. In some cases, the state studies or plans are so new that the published documents are not yet available. The purpose of the present section is to briefly review existing published studies or state program descriptions with a focus on methods and outcome and thereby to provide a background for current national trends in statewide service delivery systems.

North Carolina

The North Carolina program for persons with autism, Division TEACCH (Treatment and Education of Autistic, psychotic and Communications handicapped CHildren), is one of the best known programs nationally as well as the source of numerous published articles. The program was organized to provide a comprehensive range of services individualized according to the needs of each child and his or her family. Since being mandated by the North Carolina state legislature in 1972, it has been a separate Division within the Department of Psychiatry of the School of Medicine at the University of North Carolina (Marcus, Semrau & Scholpler, 1977). The current TEACCH program represents the expansion and further development of an earlier research project which was designed to demonstrate the feasibility of training parents to function as co-therapists with their own psychotic children. The program was the first one to be endorsed by NSAC.

Illinois

The Illinois Autism Study (Higgins, 1979) was jointly sponsored by the Illinois Department of Specialized Education Services and the Governor's Planning Council on Developmental Disabilities. An Autism Advisory Committee was employed to provide input regarding recommended courses of action and to review study materials. The methodology utilized was limited to informal polling rather that more formal, statistical methods of investigation. The study includes description of the existing system, and identification of service deficits and gaps. Among the most useful outcomes were provisions for a comprehensive model continuum of services and recommendations for implementation of a wide range of services.

Tennessee

The Project to Assess Services to Tennessee Autistic Children (Project ASTAC) based its study upon a questionnaire designed to assess the perceived

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[1] Illinois, Tennessee, Delaware, Michigan, Florida, Indiana, Iowa, Maryland, Nebraska and New York.

need for services as well as the current availability and appropriateness of the services (Chilcote-Doner & Baird, 1980). Of 107 respondents, the majority were professionals in the field of autism. The outcome of the study was a final report which described the characteristics of autistic, autistic-like and related communications handicapped persons, existing services, and needs. Recommendations for families and professionals who work with persons with autism, including implementation strategies, emphasized family involvement in the service delivery system.

Delaware

The Delaware Department of Public Instruction recently released its report on services to the autistic, "General Guidelines for the Development of Programs of Special Education and Related Services for Children and Youth with Autism" (1979). The project, not an empirically based research effort, provided an overview of the service needs of persons with autism including a definition and description of autism, educational needs, placement criteria and staff training needs.

Iowa

"Autism: Assessment of Needs within Heartland Education Agency" is the title of an in-depth study completed recently in an eight county area in Iowa (Boettcher, Durbala, Kilpatrick, Rodefeld, Van Essen & Wright, 1979). The educational needs of children who exhibited characteristics of autism were studied. Trained observers completed detailed behavioral observations, interviews with teachers, reviews of student records, and behavior and language questionnaires. Children were assigned to one of four groups descriptive of the degree and kind of handicap, and for each child the most appropriate service delivery option was determined. The distribution of children by chronological age, county or residence and communication level was determined. The study suggested the need for the development of separate classes, special programming and staff inservice training.

Nebraska

The Nebraska project consists of a series of modules being developed through the joint cooperation of the Nebraska chapter of the National Society for Autistic Children, the Meyer Children's Rehabilitation Institute and the State of Nebraska Development Disabilities Unit (McGee, 1979). The basis of the study was a survey sent to over 240 parents and professionals in an effort to determine who were the most difficult to serve, barriers to service, causes of institutionalization, and needed services. The outcome was the publication of four pamphlets entitled "Recognizing Autism", "The Needs of Autistic Children and Their Families", "Guidelines to Establish Adequate Service Programs for Autistic Persons", and "Current and Future Directions in Services for Autistic Citizens". The emphasis of the program is on the development of family-based and community-based services for the multiply-handicapped, severely disabled children and adults.

Summary

The state projects reviewed shared a number of characteristics: the provision of a description of existing services, the use of surveys from small samples of respondents and the development of recommendations for needed educational services to autistic children. No statewide studies were undertaken to enumerate the actual state population of persons with autism or to evaluate existing services. Few studies addressed the needs of non-school age persons with autism with the result that the service requirements of pre-school children and adults were usually omitted. Non-educational needs such as prevention, vocational training, support services, and leisure skills were also usually given superficial attention.

III. METHODS

The methodological approaches to the study of the state service delivery system to persons with autism are complex and varied due to the breadth of study objectives. To simplify understanding of the methods used, the present section describes the instruments and procedures involved in the development of and their application to each of the five study objectives. The resulting instruments were an autism checklist, parent survey, descriptive survey of services, and an evaluation recording form.

Instruments

Autism Checklist

The Autism Checklist is a list of 44 items categorized in five major behavior areas: problems present before child 30 months of age; problems affecting language and communication; disturbed developmental rates and sequences; unusual or abnormal responses to sensory stimuli; and abnormal ways of responding to people, objects and events. The checklist was completed by the parents of persons with autism. See Appendix D for a copy of the Autism Checklist, the NSAC and a shortened version of the NSAC definition; and the DSM-III definition of autism.

The Autism Checklist was developed in a two-step process beginning with a review of the literature and a combination of expert and "field" feedback. The literature was scanned for information regarding characteristic behaviors leading to a diagnosis of autism and for checklists and scales currently in use across the United States. The selection of items for the checklist was based primarily upon items found in the definition used by the National Society for Autistic Children as well as a number of other current scales. A draft checklist was sent to nationally recognized experts in autism and the members of the Advisory Committee for their reactions. After additional refinements, the final instrument was approved for use by the Advisory Committee.

Parent Survey

The Parent Survey is a 98 item questionnaire designed to solicit information in two major areas: 1.) demographic information about the person with autism and their family including questions pertaining to diagnosis, evaluations, and history of services; and 2.) information concerning the person's present and future service needs based on the same "continuum of services" used within the descriptive survey and the evaluation form.

The parent survey draft was initially constructed, then later reviewed by research staff members and Advisory Committee members. Following revision, the Parent Survey was field-tested by five parents who provided feedback regarding the ease of completion and clarity of content of the survey. Parent feedback was integrated into the survey and a final form completed. Appendix E presents the Parent Survey.

Survey of Institutions of Higher Eduction

The Survey of Institutions of Higher Education is a brief questionnaire consisting of questions regarding the number and nature of courses offered within colleges and universities in Virginia that study the subject of autism. See Appendix Q for a copy of the survey.

Descriptive Survey

The Descriptive Survey is an instrument designed to collect information from service providers regarding services for persons with autism in a simple "yes-no" format. The categories of services were coordinated with the service categories used in the Parent Survey and those used on the Evaluation of Services. In addition to the checklist of services, the Descriptive Survey also requested information on characteristics of the persons receiving those services, information on characteristics of services being provided, and information on subsequent service needs.

The Descriptive Survey was primarily developed from information in the literature regarding service needs of persons with autism. In addition, the Advisory Committee provided initial input into the development of the survey. The first draft of the survey was field tested by seven service providers to obtain feedback with regard to "feasibility" (ease and accuracy with which the survey could be completed) and "conceptual integrity" (comprehensiveness of the items). The survey was also submitted to three nationally recognized experts for their comments regarding the service descriptive section of the survey. Finally, all members of the Advisory Committee were asked for comments regarding the revised draft. See Appendix F for the final draft of the Descriptive Survey.

Evaluation Form

The Evaluation Form is a 838 item questionnaire about direct and indirect services; the "continuum of services", together with more detailed items, is the basis of questions regarding direct services. The evaluation criteria are categorized into three major dependent variables: 1.) "status" (degree of implementation), 2.) "evaluation" (level of acceptability), 3.) "importance" (value of potential needed improvement to facility respondents). See Appendix G for a listing of the variables on the Evaluation Form.

The Evaluation Form emerged from a variety of sources; a review of the literature pertinent to evaluation theory and methods, input from the Advisory Committee, input from technical experts within the Department of Mental Health and Mental Retardation, and a prototype evaluation format used in the "Needs Assessment Index" developed by the Virginia Association of First Chance Projects in cooperation with the Virginia Department of Education, Division of Special Education, Office of Early Childhood Programs. Because many diverse facilities were to be evaluated in order to appraise the overall system of services in the state, the objective in devising

the Evaluation Form was to create a simple yet comprehensive, quantifiable, and objective instrument, one which would maximize the likelihood of cooperation from facility representatives. It was felt that evaluation should not only assess the effectiveness of direct services to persons with autism, but should also include evaluations of administrative and indirect services.

Items for the Evaluation Form were drawn from many sources, including the continuum of services list in the Descriptive Survey, an agency evaluation form used by Mental Health and Mental Retardation for indirect services, and state licensing regulations. The preliminary draft of the Evaluation Form was sent to experts in the field of autism as well as to experts in evaluation and research. Concomitantly, practice site evaluations were conducted at the School for Contemporary Education and Grafton School to detect any difficulties in the organization, completeness and administration of the instrument. Two preliminary drafts of the Evaluation Form were written before a final version was completed. Appendix G contains a listing of the items on the Evaluation Form together with the evaluation criteria.

Procedures

Operational Definition and Autism Checklist

A short definition of autism[1] contained in a published brochure was sent to professionals, who could be expected to contact parents as potential respondents in the study. Additionally, the short definition was sent to parents who contacted the research staff expressing a willingness to participate. All parents so contacted were then sent a copy of the Autism Checklist in addition to the Parent Survey. The short definition, finally, was sent to all agencies as a part of the effort directed toward describing services in the state.

Enumeration

Enumeration of persons with autism began with contacts to 3,910 professionals, parents and facilities. Each was sent a mailing comprised of a brochure describing the study together with a cover letter and letters of endorsement. The brochure explained the nature and purpose of the study, provided the short definition or autism, and indicated how the reader could help, namely, by urging parents of persons with autism to complete an identification form to be returned to the research staff. The accompanying cover letter to professionals requested that they distribute the brochures to parents of persons with the characteristics of autism listed in the brochure. See Appendix H for a sample brochure.

Survey of Institutions of Higher Education

Implementation of this aspect of the study involved a mailing of the survey to the psychology and education departments of 38 colleges and universities in Virginia. See the list of institutions contacted in Appendix Q.

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[1]The short definition of autism consisted of the five major behavior characteristics on the Autism Checklist.

Description of Services

An initial survey, a two page "Preliminary Information for Local School Division" form, was sent under a cover letter to all Virginia school divisions from the State Director of Special Education Program Services, James T. Micklem, and included a short definition of autism. The information requested regarded whether or not the division provides services to children with autism or with characteristics similar to those of autism. If the division indicated that it was providing any such services, a Descriptive Survey of Services was sent, also accompanied by a cover letter from the State Director of Special Education Program Services. Two follow-up telephone calls were made to each division that received, but had not returned, the Descriptive Survey. In a few instances the survey was completed by telephone. All other known service providers in the state received a cover letter plus a Descriptive Survey. Facilities which received, but had not returned the survey were contacted by telephone and encouraged to complete the form.

Evaluation

The objective of this phase of the study was to evaluate a sampling of facilities responding to the Descriptive Survey. The selection criteria were as follows: 1.) the facility advertised services to autistic and autistic-like persons and/or 2.)the facility served more than three persons with autism. An attempt was also made to evaluate facilities that offered an unusual, one-of-a-kind service to persons with autism (such as respite care). Twelve facilities were contacted and invited to participate in evaluations. Site evaluations were subsequently conducted in May, June and July, 1980, at a variety of public schools, public and private facilities including the Fairfax County Public Schools, Stafford County Public Schools, Roanoke County Public Schools and Salem City, Western State Hospital, Augusta County Public Schools, The School for Contemporary Education, The DeJarnette Center for Human Development, Eastern State Hospital and Grafton School. Three sites serving smaller populations were contacted for evaluation by telephone. Each site visit team consisted of two or more professionals, usually research staff members or Advisory Committee members assisted by colleagues with experience in the field of autism. A combination of interview and observational techniques were employed in order to rate each item. Judgements were made by facility representatives regarding the item rating; consequently, evaluation data essentially reflects the evaluation of the facility by the staff.

Advisory Committee

Throughout the many months required to complete the study, the Advisory Committee was an important and integral part of the research process. The committee was comprised of individuals who represented key agencies in the state, technical experts, and parents of persons with autism. The role of the Advisory Committee was to make timely input in all aspects of the study, from refining and clarifying study objectives to reacting to proposed procedures to suggesting ways to "cut red tape". In order to solicit input from the Advisory Committee in an orderly fashion, two conferences were held during the research project. In

December, 1979, the group convened to review the organizational plans developed at that date, to assist in the refinement of specific objectives, and to provide feedback on the preliminary work on several of the instruments. The group was gathered together again in July, 1980, to review the preliminary results obtained from the study and to make suggestions for the final format of the study. The final activity of the committee was to review the final results and to discuss specific recommendations for the Developmental Disabilities Unit. Members of the Advisory committee were also available on an "as needed" basis during the year to provide input regarding specific problems or concerns that arose. See Appendix B for a listing of the Advisory Committee membership including names of members, affiliations, address, and representation.

IV. RESULTS

Autism Checklist

Autism checklists were completed by 130 parents. See Appendix I for the numbers and percentages of parent responses to the Autism Checklist.

Classification of Persons with Autism

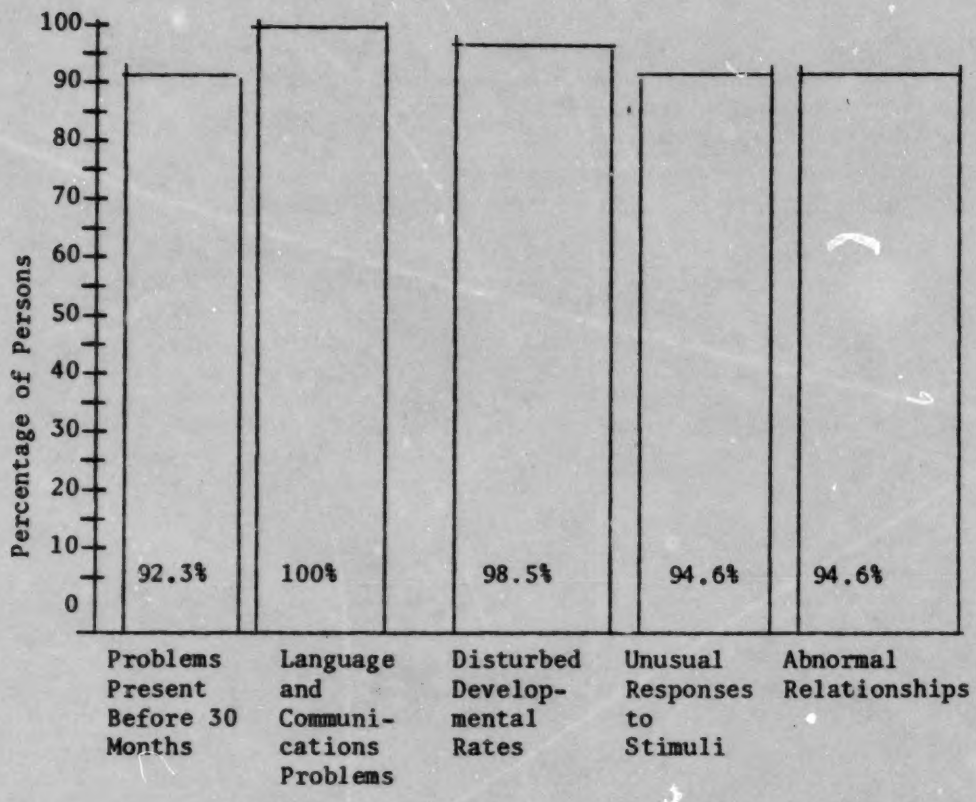
An evaluation of the 130 checklists suggests that, for the purposes of the study, 127 of the persons (98%) could be classified as "autistic" while 3 of the persons (2%) could be classified as "autistic-like". The criteria for classification was as follows: four or five major categories checked by parents resulted in a classification of "autistic", while three major categories checked resulted in a classification of "autistic-like". If fewer than three major categories had been checked the person would be considered neither autistic nor autistic-like.

Characteristics of Persons with Autism

Figure 1. presents the percentages of the 130 checklists that indicated the presence of characteristics from each of the five major behavior areas. Most notable is the fact that characteristics from each of the five areas were indicated in an extremely high percentage of the responses (ranging from 92.3% to 100%). Because the population being described consists predominantly of persons who had an independent formal diagnosis of autism, it seems safe to assume that the five areas in combination are characteristic of autism. Of the five major areas, language and communication problems were the most commonly observed characteristics in autistic persons (100%), followed by disturbed developmental rates and sequences (98.5%). Unusual responses to stimuli and abnormal relationships were observed in 94.6% of the sample. For 92.3% of the persons, characteristics of autism were noted before the age of 30 months. Note that this latter item does not mean that for 7.7% of the persons the syndrome was not present before 30 months of age, only that in retrospect the family did not recall having noticed characteristics of autism prior to 30 months of age.

Language and Communication. Within the area of "Problems Affecting Language and Communication", the most frequently observed characteristics included limited understanding of abstract terms or concepts (82.3%), problems understanding communication from others (77.6%), and failure to use speech for social communication (76.9%). An adjustment for mutism (achieved by subtracting the 53 mute children from the total number of responses) suggested that echoing or repeating others (96.1%) and poor control of pitch, volume and intonation (96.1%) also represented high frequency language characteristics. Overall, not only did all of the respondents indicate at least one problem affecting language and communication, but nearly three-fourths (74.1%), when adjusted for mutism, indicated each of the other specific characteristics.

Figure 1.



Behavior Characteristics of 130 Autistic Persons as Described by their Parents on the Autism Checklist

Developmental Rates and Sequences; Responses to Stimuli. The major characteristics found within the category of "Disturbed Developmental Rates and Sequences" was the disruption of normal coordination of the three developmental pathways (86.9%) while within the category of "Unusual or Abnormal Responses to Sensory Stimuli" the most frequently reported problem was repetitive movements such as hand shaking and spinning (72.3%).

Relations with People, Objects and Events. In the final category, "Abnormal Ways of Relating to People, Objects and Events", all three sub-areas of abnormalities of social development, ritualistic behavior, and lack of appropriate play were frequently noted (93%, 89.2% and 84.6% respectively). With regard to abnormalities of social development the most typical characteristics were: "isolates self from others" (73.0%), "poor eye contact" (74.6%) and "does not reciprocate in social interactions" (75.3%).

Summary. In summary, 98% of the persons described by their parents on

the Autism Checklist were considered to be autistic, while 2% were considered to be autistic-like. The likelihood that the majority of persons studied are, in fact, autistic is strengthened due to the fact that most of the persons had also been independently diagnosed as having autism. These findings also lend credibility to the Autism Checklist as a promising screening instrument.

Description and Enumeration of Persons with Autism

The results of the enumeration of persons with autism in Virginia are based on 118 parent responses to questions posed by Parent Survey. Since a varying number of respondents failed to answer some questions, percentages are based on the actual number of respondents for each question (adjusted frequencies). Also, due to the large amount of data generated by the enumeration phase of the study, further analyses were completed by grouping the data into meaningful variables such as characteristics of the autistic persons, type of facility and geographical location. The interactions of the variables were studied by chi square analysis.

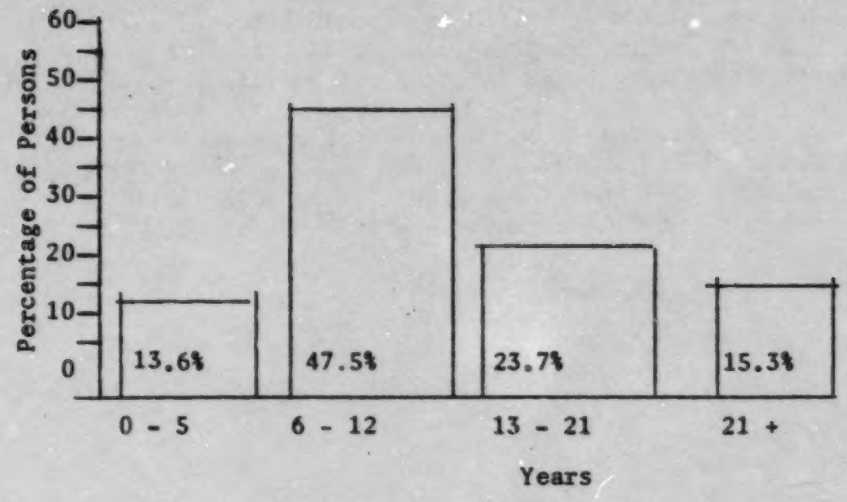
Location of Persons with Autism

Parent Surveys completed and returned numbered 118 and were from 40 counties and cities throughout the state. Appendix J lists the frequency of responses to the Parent Surveys according to city or county together with a map of the locations of the persons with autism. Surveys were predominantly received from the northern Virginia area with nearly 42% of all responses from HSA #2. Other smaller concentrations of responses were from Tidewater area (13%), the Roanoke are (12%), and the Richmond area (12%). Only 7% of the responses were from other than these four areas. While the four areas are the larger population centers in the Commonwealth, the number of autistic persons enumerated is nonetheless disproportionately represented. Fairfax County, for example, contains 10.5% of Virginia's population according to 1978 estimates, yet 23.7% of the enumerated persons were from Fairfax County. Clearly awareness about identification of as well as services for the autistic are not uniformly evident throughout the Commonwealth.

Characteristics of Persons with Autism

Age, Sex and Race. The distribution of responses was skewed not only geographically, but also in terms of age. See Figure 2. for an illustration of the age distribution of persons studied by the project. Sixteen persons (13.6%) were 0 - 5 years old, 56 persons (47.5%) were 6 - 12 years old, 28 persons (23.7%) were 13 - 21 years old and 18 persons (15.3%) were over 21 years. Ninety-three (78.8%) of the autistic persons were male white, 14 (11.9%) persons were black, and 4 (3.4%) persons were an "other" race.

Figure 2.

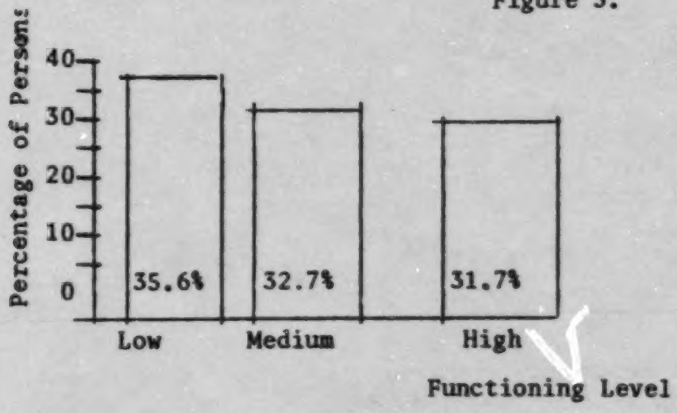


The Age Distribution of Persons
With Suspected Autism

Functioning Level. Parents were next asked to describe the functioning level of the person with autism in five areas: intelligence, self care, social skills, behavior and communication; see Appendix E for the operational definitions of each area of functioning.

In the area of intellectual functioning, 114 persons with autism described by their parents appeared to be evenly distributed across levels of functioning as shown in Figure 3.

Figure 3.

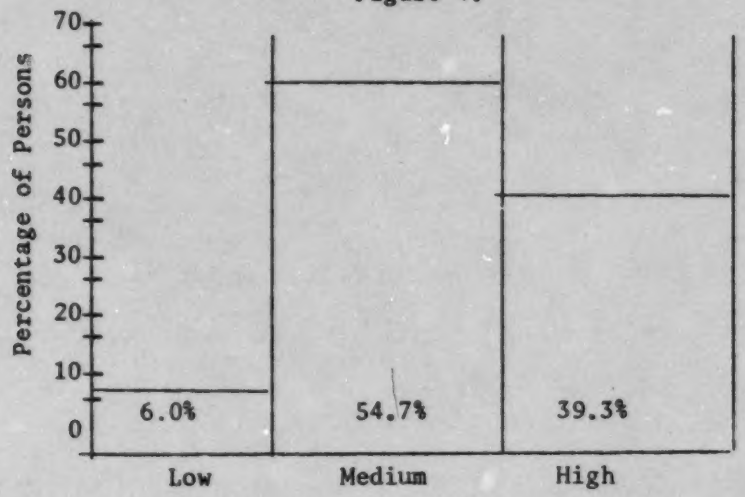


Level of Intellectual Functioning of
114 Persons with Suspected Autism

That is, 37 (35.6%) persons were described as low (IQ below 50), 34 (32.7%) were described as medium (IQ 50-69) and 33 (31.7%) were described as high (IQ 70 or over) with regard to intellectual functioning.

In the area of self care abilities, 117 persons with autism were described as demonstrating medium to high levels of functioning, that is, partial or complete ability to feed, dress, and toilet self. See Figure 4. for a summary of self care functioning.

Figure 4.



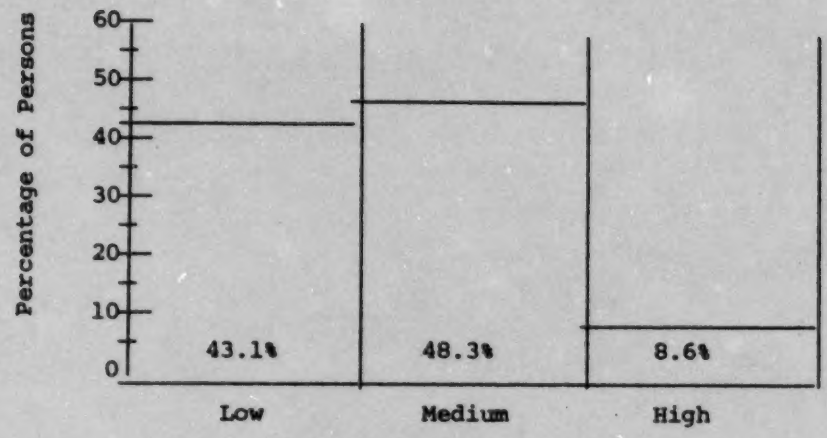
Level of Self Care Functioning of
117 Persons with Suspected Autism

Thus, few persons (7 or 6.0%) appeared to display the inability to feed, dress or toilet themselves without assistance; however, the majority (64 or 54.7%) were only partially able to perform these basic self care functions while 40% (46) were considered independent in these areas.

The social abilities of 116 persons with autism were frequently described as being developed to a low or medium degree; for instance, the persons use toys and materials inappropriately and engage in either solitary play or activities with one age-mate. See Figure 5. for a summary of social functioning. Overall, most persons demonstrated low (50 or 43.1%) or medium (56 or 48.3%) social skills while only 10 (8.6%) demonstrated appropriate use of toys or materials and pursued social contact.

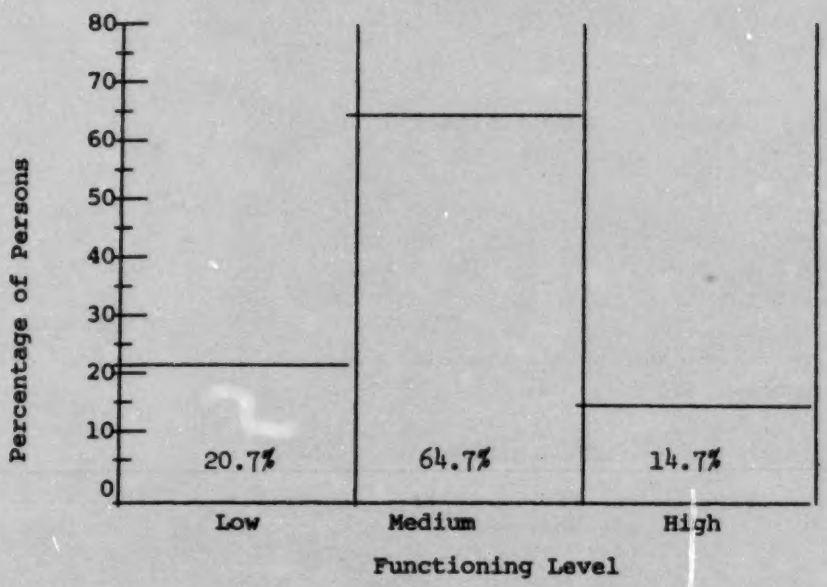
In terms of behavior, the majority of 116 persons with autism were considered to display intermittent or mildly bizarre or destructive behaviors (medium level of functioning), as shown in Figure 6. That it, 24 (20.7%) of the persons manifested low and 75 (64.7%) showed medium levels of behavioral functioning; only 17 (14.7%) showed the absence of bizarre or destructive behaviors.

Figure 5.



Level of Social Functioning of 116 Persons with Suspected Autism

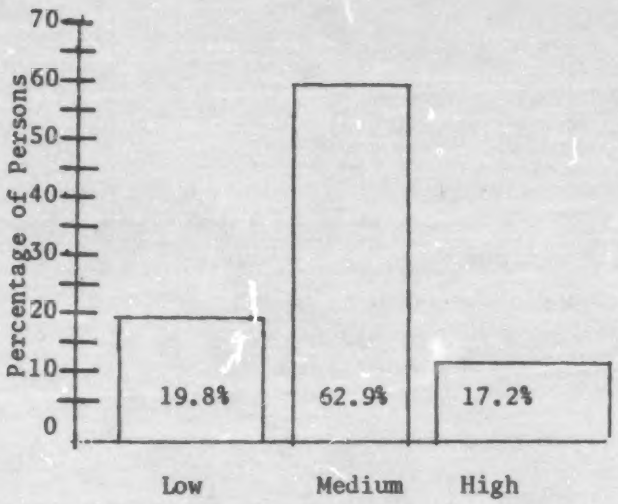
Figure 6.



Level of Behavioral Functioning of 116 Persons with Suspected Autism

Finally in terms of communications skills, the data regarding 116 persons with autism is presented in Figure 7. Most typically the persons were considered able to communicate basic needs and wishes through verbal or gestural language (73 or 62.9%). Nearly one-fifth (23 or 19.8%) were considered to tack communicative intent, and only 17.2% (20) to demonstrate conversational speech.

Figure 7.



Level of Communication Functioning of
116 Persons with Autism

Summary. In summary, if the modal (most frequently occurring) responses of parents are combined, the composite picture of the typical person with autism reported in Virginia is a white male, between the ages of 6-12 years. The person with autism does not demonstrate conversational speech, though he/she is able to communicate basic needs. The person demonstrates intermittent or mildly bizarre or destructive behavior and does not use toys or materials appropriately nor readily approach age-mates.

Family Experiences in Obtaining Diagnostic Services

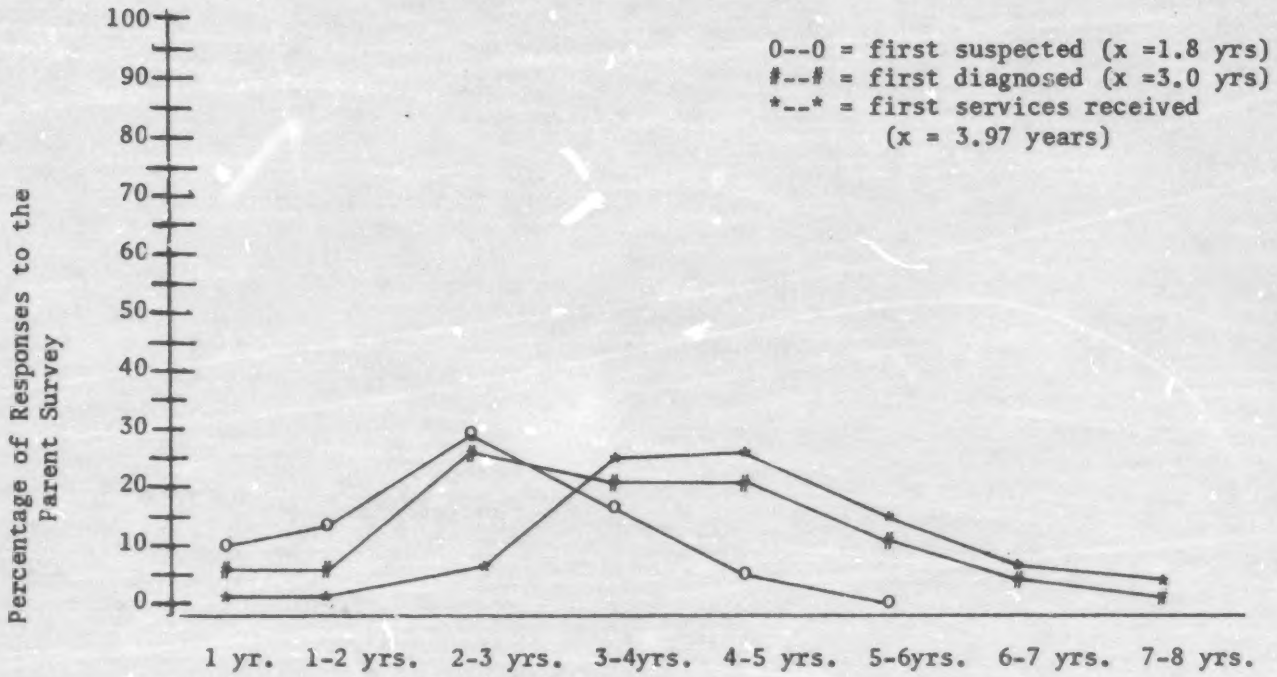
The next section on the Parent Survey was composed of questions designed to elicit information regarding the kinds of experiences the families had had in obtaining disgnostic services for their autistic family member.

The first question asked parents to name the person who first suspected that their child had a handicapping condition. Responses by the parents indicated that 71.2% of the families themselves first suspected that their child had a handicapping condition; parents were followed, in order, by others such as relatives, tutors and school personnel (11.9%), the family

together with the pediatrician (5.9%) and the pediatrician alone (4.2%) as the sources of initial concern about a handicapping condition in their child.

The next question regarded a determination of what age the child was when the parents first suspected that he/she had a handicapping condition. The majority of the parents (64.0%) responded that their child was less than three years old when they first suspected a handicapping condition; 3.2% said their child was less than one year old, 25.2% said their child was between two and three years old when the handicap was first suspected. The average age of the child when suspected of having a handicap was 1.8 years. See Figure 8. for a summary of responses to this question and comparison with the two subsequent question.

Figure 8.



A Summary and Comparison of the Ages at which Persons with Autism were First Suspected to Handicapped, were First Diagnosed and First Received Services.

Parents were then asked to state the child's age at the time of his/her first diagnosis of a handicapping condition. For the majority of families (51.5%), the first diagnosis occurred when the child was between the ages of two and four years, with an average of 3.0. Only 9.8% received a diagnosis before the age of two, while 38.7% received diagnosis after the age of four.

Finally, parents were asked to describe the age of the child when he/she first received services for a handicapping condition; the average age was found to be 3.9 years. Those receiving services before the age of three comprise 16.6% of the sample, while those receiving services after the age of four were 53.7% of the sample. It is unknown for how many of the families the "first services" were also diagnostic services as opposed to education and training services.

Regarding diagnostic experiences, several additional questions were posed. One result was that all of the respondents indicated that their child was diagnosed as "autistic" or "autistic-like". In addition, however, 30.5% had multiple diagnoses. See Appendix K for the percentages of diagnostic labels, including a listing of "other" diagnoses as reported by parents. Parents were also asked to indicate the location in which the diagnosis was made. The answer to this question were analyzed for the sake of simplicity into three categories: diagnoses were made either 1.) in-state (59.0%), 2.) out-of-state (37.3%) or 3.) both in-state and out-of-state (5.9%). Appendix L lists the diagnostic centers utilized by parents. Further, most of the parents (77.5%) reported that they traveled 0-50 miles to obtain diagnostic services. A small number of parents traveled greater distances: 6.9% traveled 50-100 miles and 15.6% traveled over 100 miles.

Summary. To summarize, the average age when a handicapping condition was first suspected was 1.8 years, the average age when the handicap was first diagnosed was 3.0 years, and the average age when first services were receieved was 3.97 years. In all, more than two years passed after the typical person with autism was noticed as handicapped and efforts were begun to ameliorate the handicap. It is important to note that the "handicapping condition" first suspected, diagnosed and served was not necessarily autism, for many of the autistic persons have received multiple diagnostic labels over time.

The parents of the present sample of 118 persons with autism reported that their children were usually diagnosed as autistic and/or autistic-like; however, in many cases it was necessary to obtain diagnostic services outside Virginia requiring travel of more than 50 miles. Further, many of those parents who traveled less that 50 miles traveled out ot state to obtain diagnostic services (usually to Washington, D.C.).

History of Services

A total of 83 parents completed a section on the survey about the services received in the past by their children. A critical variable in the services received was the reason for leaving programs; see Table 1 for a summary. Among parents responding, nearly two-thirds mentioned negative reasons for leaving programs, such as "unsuitable program", "age limits", "asked to leave", "program ended", and so on. Not one parent mentioned "graduation" as a reason for leaving a program, although one in ten parents stated their child left a program for public schools. In all, persons with autism in Virginia have attended three to four programs with an average stay of less than two years.

Table 1

Reasons for Leaving Programs

Reasons	Frequency	Percent
Program was inappropriate/ unsuitable	40	25
Reached Age limit	21	13
Moved	19	12
Transferred	17	11
Recommended/asked to leave	17	11
Program ended	16	10
Went to public school	15	9
Problems with Insurance/ finances	8	5
To be closer to home	4	3
Person was too large/ aggressive	3	2
Total	160	100

It was also found that of the families responding to the Parent Survey, 13 (11%) had another handicapped person in the family. The most commonly occuring handicaps were epilepsy, autism and mental retardation.

Parent Description of the Service Setting

The nature of the service setting of the persons with autism was described next by their parents. A rather surprisingly large percentage of parents (53.8%) responded that their children were not presently placed in programs designed for the autistic. It was found also that, among parental respondents, 39.6% had children placed in day programs, 50.6% had children in residential programs, and 9.8% had children who were

currently not placed in any programs.

Services Currently Received by Persons with Autism

The final set of questions were organized around the "continuum of services." The continuum or listing of various services also served as the basic dimension for organizing descriptive data from facilities serving the autistic and evaluation data regarding services provided. Consequently it is important to become familar with this continuum in order to better understand much of the remaining results and discussion. Table 2 presents the major headings of the continuum. Each of the seven major headings are further defined with a series of specific services in the actual assessment instruments.

Table 2

Continuum of Services - Major Headings

1. Identification
2. Education, Training, or Treatment/Growth Services
3. Related Support Services
4. Family Services
5. Employment Services
6. Living Services
7. Social, Legal, Information Services[1]

As part of the Parent Survey, families were asked to indicate those services which were presently needed, those services received, satisfaction regarding those services received, and finally those services they will probably need in the future. Appendix E contains the Parent Survey and Appendix N contains the family responses to the questions related to the continuum.

The results and levels of significance presented in Appendix P are analyzed in terms of three questions of interest: 1.) services currently needed, 2.) services needed in the future, and 3.) lack of satisfaction with services currently received. Significant parent responses to the continuum of services are presented below in Table 3.

Current Service Needs. Responses from parents indicated that the relatively most pressing needs at present are concentrated in the area of Related Support Services. Counseling, psychotherapy, and psychological consultation were frequently noted suggesting deficits in psychological services. Recreation and social work services were also mentioned as

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[1]Not on the Parent Survey

present needs. The area of Education and Training was also characterized by many needs, primaily in those designed to teach socialization skills: use of leisure time, use of community resources and planned experiences with non-handicapped individuals. Training in a total communication system and vocational instruction were also designated by parents as current needs. Finally, Family Services, specifically training and counseling, were indicated as current needs. Significant current needs were not mentioned by parents in the area of Identification, Employment Services or Living Services.

Table 5

Parent Responses to the Continuum of Services

Service	Current Need[1]	Future Need[2]	Not Satisfied[3]
I. Identification			
2. Evaluation		x	
II. Education, Training, or Treatment/ Growth Services			
A. Language Development			
1. language training		x	
2. speech therapy			x
3. sign language			x
4. total communication system	x		
B. Socialization			
1. play skills		x	x
2. peer interaction		x	x
3. interaction w/authority		x	x
4. group interaction		x	x
5. emotional expression		x	x
6. use of leisure time	x	x	x
7. use of community resources	x	x	x
8. money management		x	
9. use of public transportation		x	x
10. planned experiences with non-handicapped individuals	x	x	
C. Personal Independent Skills			
1. grooming		x	
2. hygiene		x	
3. housekeeping		x	
4. care of personal items		x	
5. independent living		x	x
D. Academic Instruction			
1. language arts			x
2. math		x	
3. social studies			x
4. science			x
5. physical education		x	x
E. Specific Programming to Remediate Maladaptive Behaviors		x	x

Table 3 (continued)

Service	Current Needs	Future Need	Not Satisfied
F. Prevocational Instruction		x	x
G. Vocational Instruction	x	x	x
H. Expressive Development			
1. dance			x
2. music		x	x
3. art		x	x
III. Related Support Services			
A. Transportation		x	x
B. Recreation	x	x	x
C. Counseling	x	x	
D. Psychotherapy	x		x
E. Psychological Consultation	x	x	
F. Speech Pathology or language training		x	x
G. Social Work	x		
H. Audiological			x
I. Health - medical			x
J. Music, Dance, or Art Therapy		x	
K. Nutritional/dietary Evaluation			x
IV. Family Services			
A. Training	x	x	
B. Counseling	x		
C. Respite			x
D. Support			
1. Parent - parent support			x
V. Employment Services			
A. Sheltered Employment		x	x
B. Supervised/subsidized Employment		x	
C. Vocational Rehabilitation		x	
VI. Living Services			
A. Adult Day Care		x	
B. Leisure/recreational Resources		x	x

Future Service Needs. The future service needs of persons with autism were most heavily represented in Education and Training Services; virtually every item comprising socialization and personal independent skills was noted as a future need by parents. In addition, a smattering

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[1]Significance level: + 1 S. D.
[2]Significance level: + 1 S. D.
[3]Significance level: 50% or greater

of other educational and training services were indicated as needed in the future: language training, math, physical education, specific programming to remediate maladaptive behaviors, prevocational and vocational instruction, and music and art therapy. Evaluation was mentioned as a future need within the area of Identification Services. Many future needs were again noted by parents in the area of Related Support Services including transportation, recreation, counseling, psychological consultation, speech pathology or language training, and music, dance or art therapy. Future Family Services needs were found to be represented by training for families. Unlike the findings for current service needs, future service needs were often indicated by parents in the areas of Employment Services and Living Services; the needed future services were sheltered employment, supervised/subsidized employment, and vocational rehabilitation; adult day care and leisure/recreational resources, respectively. Thus, in no major area of services did parents indicate a lack of future needs.

Lack of Satisfaction with Services Currently Received. The surveys completed by parents who indicated their children were currently receiving specific services designated on the continuum of services were next inspected to determine the satisfaction with those services. Only those services with which parents indicated a lack of satisfaction are discussed here. Interestingly, the services which were most frequently noted as not satisfactory were those same services which were often indicated as current and future needs. That is, in the area of Education and Training Services, a total of eight different socialization services were indicated as not satisfactory; also, the majority of language development services were seen as not satisfactory, as were many of the items related to academic instruction. The remainder of the items within the Education and Training Services area exhibited a smattering of other unsatisfactory services such as independent living, prevocational and vocational instruction, and expressive development (dance, music and art). Once again, many Related Support Services were mentioned as not satisfactory by parents including transportation, recreation, psychotherapy, speech pathology or language training, audiological, health-medical, and nutritional/dietary evaluation. Within the area of Family Services, parents indicated a lack of satisfaction with respite care and with parent-to-parent support groups. Dissatisfaction was additionally noted in the areas of Employment Services and Living Services respectively with sheltered employment and leisure/recreational resources.

Summary. In summary, the premier needs of persons with autism as indicated by their parents appear to be in the area of Education and Training in socialization, specifically services designed to teach the use of leisure time and community resources. Vocational training was another service which received many responses by the majority of parents, that is, "current need", "future need", and "not satisfactory". When the items were analyzed to detect what might be the greatest needs of persons with autism (that is, were characterized by two out of three of the following responses: "current need", "future need", "not satisfactory"), Education and Training in socialization was again an important service area according to parents. Additional service needs described by parents in the area of Education and Training were language training, total communication, specific

programming to remediate maladaptive behaviors, prevocational instruction, and expressive development. The major services of interest to parents in the area of Support Services were transportation and various psychological services. Family Services, Employment Services, and Living Services were characterized by strong needs for family training, sheltered employment, and leisure/recreational services respectively.

Other Aspects of Services Currently Received

Following an analysis of the results of global responses to the continuum of services by parents, the results were next examined to determine whether significant differences might be found taking into consideration: 1.) age of the autistic person and service needs, and 2.) characteristics of the autistic person and other programmatic aspects.

Autistic Person's Age and Service Needs. The first variable examined was that of age; four age groups of autistic persons were examined: 1.) 0 - 5 years, 2.) 6 - 12 years, 3.) 13 - 21 years, and 4.) over 21 years old. Using a chi square analysis, interactions which were significant at the 0.5 level or greater were studied further; when the percentage of responses among age groups are significantly different, the results are presented for discussion. The service need dimensions considered include: "present needs", "not satisfied with services received", and "future needs". See Table 4 for a summary of the results of the four age groups within the continuum of services.

Table 4

The Present Needs, Satisfaction and Future Needs of Four Age Groups on the Continuum of Services

Service	Ages			
	0 - 5	6 - 12	13 - 21	+ 21
Play Skills		Not Satisfied	Not Satisfied	Not Satisfied
Independent Living			Present Needs	Present Needs
			Not Satisfied	
Vocational Instruction			Present Needs	Present Needs
Psychiatric Consultation - to program staff regarding person served	Present Needs			
	Not Satisfied			
Adaptive physical education				Needs
		Not Satisfied	Not Satisfied	

Table 4 (continued)

Service	Ages			
	0 - 5	6 - 12	13 - 21	+ 21
Training - instruction to family in techniques for assisting person w/autism	Present Needs	Present Needs	Present Needs	Present Needs
Supervised/subsidized employment - support for employment of the chronically disabled in the natural environment			Present Needs	Present Needs
Residential services for autistic - 24 hour out of home care				Future Need
Money Management	Future Need	Future Need		Future Need
Care of personal items	Future Need	Future Need	Future Need	
Reading	Future Need	Future Need		
Language Arts	Future Need	Future Need		
Social Studies	Future Need	Future Need		
Science	Future Need	Future Need		
Respite - temporary or emergency care		Future Need	Future Need	

The results suggest that when the four age groups are analyzed, the age groups of 13 - 21 years and over 21 years old most frequently show present needs. Thus for the 13 - 21 years old group, the following "present needs" distinguished this group from the remaining groups: training in independent living, vocational instruction, psychiatric

consultation, family training, and supervised/subsidized employment. As compared to other age groups, the parents of the 13 - 21 age group were not satisfied with the following services presently received by their autistic children: play skills, training for independent living and adaptive physical education.

Within the over 21 years old group, the following present needs were identified more often than for other age groups: training for independent living, vocational instruction, adaptive physical education, family training, supervised/subsidized employment, and residential living for adults. The parents were more uniformly dissatisfied with the play skills presently received by their children.

Summary. In summary, when four age groups were analyzed separately, the 13 - 21 years and over 21 years groups showed the most characteristic distinguishing present needs for services. The present need most frequently identified by the four age groups was family training.

Autistic Persons' Characteristics and other Programmatic Aspects. Results were analyzed to determine what, if any, interactions exist between the characteristics of the autistic persons described in the Parent Surveys and a host of program variables such as type of program (day versus residential), type of facility (advertizes services specifically for autistic), and geographic location (Health Service Agency regions). Results are presented only when interactions are significant at the .05 level or less.

The results suggest that significant differences may be found in parents' judgments of the autistic persons placed in day versus residential programs, in terms of intelligence, self care, behavior and communication skills. The percentage of autistic persons reported as having low and high skills in day and residential programs is shown in Table 5.

Table 5

The Percentage of Autistic Persons with High and Low Abilities in I.Q., Self Care, Behavior and Communication in Residential versus Day Programs

Characteristic		Program Type	
Type	Level	Residential	Day
I.Q.	High	19.2	80.0
Self Care	Low	100.0	0.0
	High	29.3	70.7
Be-havior	Low	71.4	28.6
	High	21.4	78.6

Table 5 (continued)

Characteristic		Program Type	
Type	Level	Residential	Day
Communi-cation	Low	61.9	38.1
	High	6.3	93.8

It is apparent that significant differences occur in an autistic persons' program placement when his or her intellectual functioning is relatively high (over 70); most intellectually high functioning persons are placed in day programs (chi square = 6.99, 2 d.f., $p < 0.05$). The same trend is also observable for self care (chi square = 9.52, 2 d.f., $p < 0.01$) and communication abilities (chi square = 11.84, 2 d.f., $p < 0.01$). No differences were observed in program placements of persons based on social skills. Thus, children in day programs were more frequently considered to have IQs above 70; to be able to independently feed, dress, and toilet themselves; to not exhibit bizarre or destructive behavior; and to have conversational speech than were children in residential programs. Conversely children in residential programs were more frequently rated as unable to feed, dress, and toilet themselves without assistance (100% were so rated!); as exhibiting a preponderance of severe destructive or bizarre behavior; and as being mute or lacking communicative intent.

No significant differences were found when autistic persons' characteristics were compared with facility type, that is, facilities which advertize versus do not advertize services specifically for autistic persons.

The data were next examined to determine whether any significant differences would be found among the five Health Service Agency (HSA) regions in the state according to characteristics of the autistic persons. No significant differences were found for any variables except age (chi square = 26.37, 15 d.f., $p < 0.05$). See Appendix O for chi square analysis of the distribution of autistic persons by age and HSA region.

The results of age and frequency distribution of autistic persons reveals a number of interesting facts. First, HSA II (Northern Virginia) has the highest reported population (41.5%) of autistic persons, while HSA I (Northwestern Virginia) (7.6%) and HSA V (Eastern Virginia) (6.8%) report the lowest population. Second, diverging from the statewide pattern reported earlier, that is, that the greatest numbers of autistic persons were found in the 6 - 12 years age range, HSA II is characterized

by an older population, in which 57.1% of the persons are over 13 years of age. HSA IV (Central Virginia), in contrast, shows the largest young population (37.5%) in comparison to other regions.

A final point of inquiry was to determine whether differences existed in program types (residential or day) and facility type (advertized specific services for autistic persons). Taken together, nearly half the parents (40%) of persons placed in residential and day programs stated that the program was an advertised facility (chi square = 8.38, 2 d.f., $p < 0.05$).

Summary. When the characteristics of persons with autism were studied vis a vis other program variables, a number of interesting findings emerged. The majority of autistic persons enrolled in day (versus residential) programs were found to exhibit higher functioning in intellectual, self care, and communication abilities; social skills abilities among the persons studied were low in both day and residential settings. The highest population of autistic persons was found to be in Northern Virginia.

Descriptive Survey

Preliminary Information

Number of Responses to the Preliminary Survey. A total of 69 "Preliminary Information for Local School Division" forms were returned from the 139 local school divisions for a 50% return rate. Because three of the "Preliminary" forms included information in other surrounding divisions, data are included for a total of 72 divisions. Responses on the preliminary forms are presented in Table 6.

Table 6

Responses to Preliminary Descriptive Survey by 69 Local School Divisions

Survey Questions	Responses		
	Yes (%)	No (%)	N. R. (%)
1. Currently providing services to children formally diagneses as having autism	18 (26)	49 (71)	7 (10)
2. Currently providing services to children with characteristics similar to those of autism	42 (68)	22 (32)	10 (14)
3. Service provided to autistic or autistic-like: a) in classes uniquely designed for autism; b) in classes together with other identified populations	5 (7) 36 (52)	42 (61) 16 (23)	27 (39) 22 (32)

Table 6 (continued)

Survey Questions	Responses		
	Yes (%)	No (%)	N.R. (%)
4. Services secured elsewhere	14 (20)	33 (48)	27 (39)
5. Division has identified such children	24 (35)	35 (51)	15 (22)
6. Division currently serves such children	22 (32)	32 (46)	20 (29)

Of the 69 Preliminary forms, 18 indicated that the division was providing services to students formally diagnosed as having autism representing 26% of the responding divisions and 13% of all divisions. Forty-two divisions (51% of respondents and 30% of all divisions) indicated that services were provided to students with characteristics similar to those of autism but that the students were not labeled as having autism. These students were typically labeled as emotionally disturbed, mentally retarded, or multiply handicapped.

Services for Students with Autism. In terms of service, only five divisions indicated that they provided classes uniquely designed for students with autism. Most typically, insofar as services are offered, they are provided in classes designed for other identified populations, such as trainable mentally retarded, educably mentally retarded, emotionally disturbed, or multiply handicapped students.

Fourteen divisions indicated that services were secured elsewhere. Specifically mentioned were the programs operated by the State Department of Mental Health and Mental Retardation, including DeJarnette, Eastern State Hospital and Central State Hospital. Also noted were private providers including Grafton School and Sarah Bonwell Hudgins. Finally, some regional public school programs were identified as serving autistic students.

Twenty-four of the respondents indicated that they had identified students with characteristics of autism. Of those 24 divisions, 19 indicated that they were providing services for such students. An additional three divisions indicated that they were providing services but had not identified such students.

Estimated Prevalence of Students with Autism. Regarding numbers of students identified and served, full data by local school divisions is presented in Appendix P. Throughout the Commonwealth, the total school enrollment for the fall of the 1980-81 school year was 1,010,371 (Division

of Management Information Services, Department of Education, Commonwealth of Virginia). For this size population one would project, based on prevalence of 15 per 10,000[1], that there would be approximately 1,516 students with characteristics of autism included in the school enrollment. By comparison, using the most limited definitions of autism, one would expect to find 505 students of a prevalence of 4 - 5 per 10,000, in the state who are "classically" autistic. The total enrollment for the 73 divisions represented in the data on the Preliminary form is 545,671 (54% of total school enrollment). For these 73 divisions, it would therefore be projected that there would be approximately 819 students with characteristics of autism. These jurisdictions report only 49 students diagnosed with autism, and 150 estimated with characteristics of autism.

A few local school divisions were identified as providing services for the autistic who did not return the preliminary form, but who did complete the Descriptive Survey. The information contained in column (f) of Appendix P reflects the number of autistic or autistic-like students actually enrolled in services as described on the Descriptive Survey. The Descriptive Survey data provides information on an additional of nine local school divisions, eight of which are served by regional programs. These nine divisions have an enrollment totaling 165,729 students. The project thus has information regarding number of identified students with autism relating to 70% of the entire school population in the Commonwealth from 61% of the local school divisions.

Frequently information on the Descriptive Survey regarding number of students served did not agree with information from the Preliminary form. (For those divisions where data is available from both sources, 60 students of autism from either the preliminary form of the Descriptive Survey (column (g) in Appendix P) as the most generous estimate of the total number of identified students, there are a total of 217 students with characteristics of autism from 83 local school divisions with a total enrollment of 711,400. This number of identified students represents a prevalence of 3 per 10,000 within 82 divisions as compared to the generally accepted rate of about 15 per 10,000.

Although there is no direct information from 53 local school divisions, including some large divisions (most notably Norfolk, Chesterfield and Henrico), there have also been no other indications through study instruments that any of these 53 divisions are providing services to students with autism,

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[1]The prevalence rate of 15 per 10,000 was selected for the sake of simplicity as the mid point of the prevalence rate of 10 - 20 per 10,000 which is advocated for planning purposes by Wing and Gould (1979) and NSAC. The rate of 15 per 10,000 is thought to indicate the prevalence of those persons having characteristics of autism, autistic-like, and, hence, similar service needs; the rate of 5 per 10,000 refers to those persons who meet the narrower definition of autism. The authors of the present study recommend that the reader be aware of the differing rates as well as their etiologies, rationales and outcomes; the authors can not recommend, therefore, use or adaption of either rate by others who have differing purposes for such rates.

whether from families having a child with autism, from responses to the brochures mailed throughout the Commonwealth, or from the project's Advisory Committee which included representation of the State Department of Education and local school divisions. There is some basis for assuming that the 217 students represents nearly the total number of students throughout the entire Commonwealth who have been identified by local school divisions as having characteristics of autism. This would represent a prevalence of 3 per 10,000 of the total school enrollment in the Commonwealth. Consequently only 15 to 20 percent of the projected number of students with characteristics of autism of school age have been identified and only very few have been specifically diagnosed. Since only 49 students were specifically reported as diagnosed with autism, this represents a prevalence of only 0.9 per 10,000 of the enrollment of the reporting divisions!

Descriptive Survey

Number of Responses to the Descriptive Survey. In all, Descriptive Surveys were completed and returned for 41 programs. These surveys included 26 from public school programs serving 41 public school divisions. In addition there were 10 private non-profit programs, and five state institutions.

Twenty-two public school divisions indicated on the Preliminary Form they were providing services to autistic or autistic-like students who did not also respond to the Descriptive Survey. Most of the 22 public school divisions indicated they were providing services to only one autistic student, and of these only five were formally diagnosed as autistic. Four of the non-responding divisions reported serving only two students with autistic characteristics. Only three of the divisions not responding to the Descriptive Survey indicated that they were providing services to the number of autistic or autistic-like students commensurate with the projected incidence for the division. The City of Alexandria reported serving 10 students with characteristics of autism including three specifically so diagnosed; Carroll County reported serving seven and Gloucester County six students with characteristics of autism. It would appear therefore that the Descriptive Data pertaining to the 41 public school divisions represents information on most of the public school services in the Commonwealth, with the exception of the above three noted divisions.

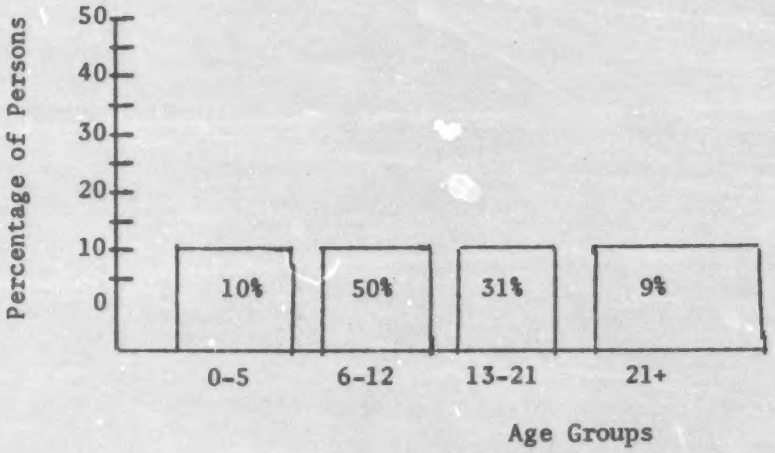
For potential service providers other than public schools, there were 11 Descriptive Surveys sent that were not returned. It is difficult to understand the meaning of these "no responses" because they do not come from a well defined service system. Those failing to respond to the Descriptive Survey of whom it had somehow been indicated that they were providing services for autistic persons included mental health centers, a sheltered workshop, a specialized foster care program, a regular private preschool, a child development center, a geriatric psychiatric hospital, and private special education program.

Characteristics of Served Persons with Autism. The first question on the Descriptive Survey requested demographic information on the persons with autism served by the program. Information was identical to that requested from parents on the Parent Survey regarding age and functioning level in the five areas defined earlier.

Overall, the 41 reporting agencies (public schools, state institutions, and private non-profit facilities) provided demographic data on a total of 252 persons with characteristics of autism currently receiving service.

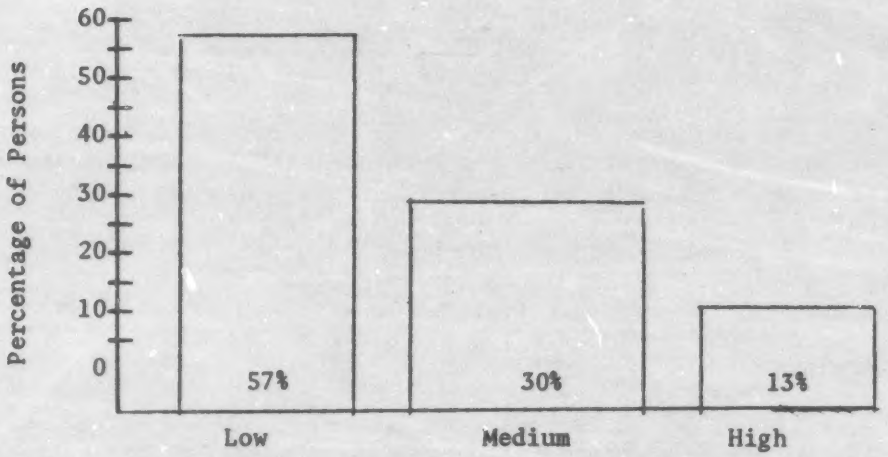
Regarding age (see Figure 9), the predominantly served population is in the 6-12 years age range; half of the 246 cases where age was presented were in that age range. In addition, 80% of the reported cases were in the 6-21 age range. Slightly less than 10% were below age 6, and slightly less than 9% were above age 21. The ages reported ranged from 2 to 35 with a mean of 12.06 years, a median of 10.33, and a mode of 8.00 years.

Figure 9



The Age Groups of Served Persons with Autism

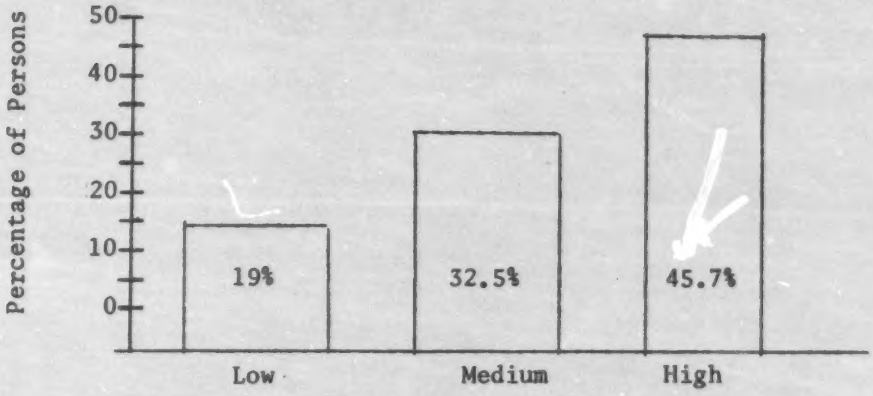
Figure 10



The Intelligence Level of Served Persons with Autism

In terms of intellectual functioning (see Figure 10) the majority of served persons (57%) were rated as having an IQ below 50, and 86.6% to have IQ's below 70. Only 13.2% of the 242 completed cases were indicated as having an IQ above 70. In the area of self care (see Figure 11) slightly less than half (45.7%) were rated as being able to feed, dress and toilet themselves. About one in five (19%) were considered

Figure 11

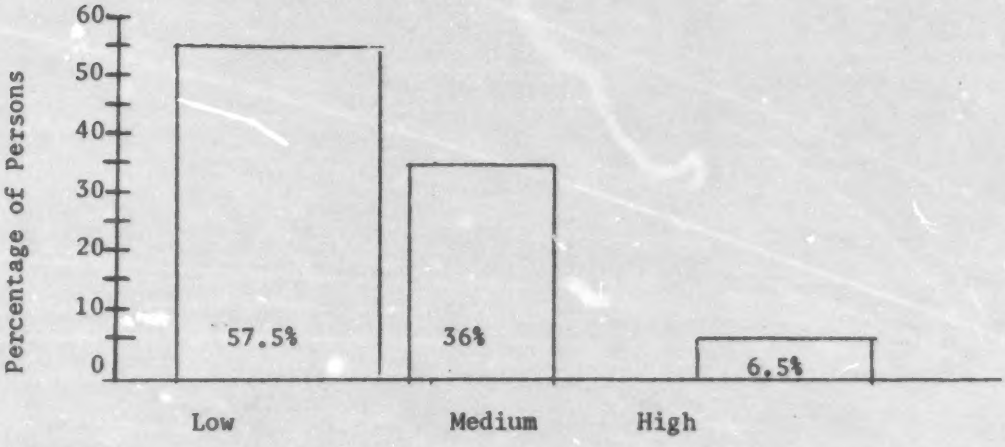


The Self Care Level of Served Persons with Autism

unable to perform these functions without assistance, and the remaining 32.5% of the 247 cases were considered partially able to perform these functions.

The area in which the most persons were rated lowest was the area of social skills (see Figure 12). Well over half (57.5%) were considered

Figure 12

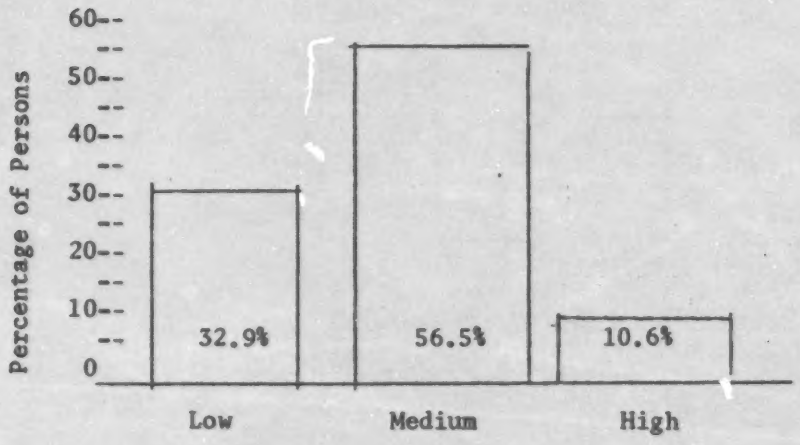


The Social Level of Served Persons with Autism

to use toys and materials inappropriately and to engage in solitary activity. Approximately one-third (36%) were considered to use some toys amd material appropriately and angage in some activity with age mates. Very few (6.5%) were rates as using most toys apprporiately or readily approaching age mates.

In terms of behavior (see Figure 13), most persons were considered to exhibit intermittent or midly bizarre or destrictive behavior. In addition 32.9% were considered to exhibit a prepondernace of severe, self-destrictiveness, stereotypic movements, and unusual reactions to stimuli. Only 10.6% were not considered to exhibit bizarre or destructive

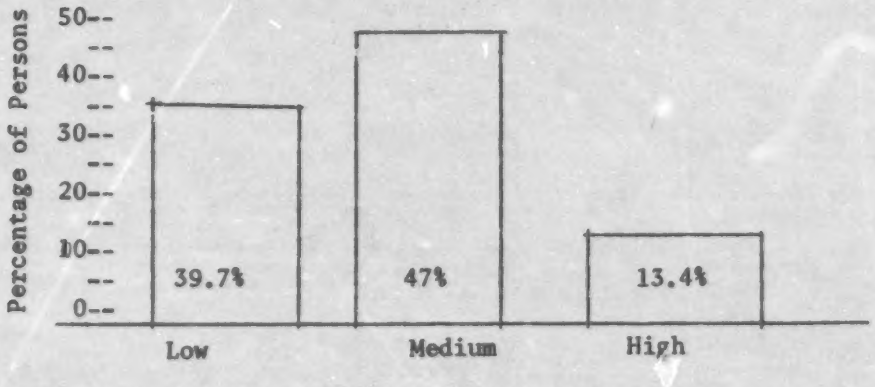
Figure 13



The Behavior Level of Served Persons with Autism

behavior. Communication level (see Figure 14) was also rated low with only 13.4% having conversational speech as compared to 39.7% considered mute or having no speech with communicative intent. Most typically persons were rated in between these extremes with 47% considered able to communicate basic needs.

Figure 14



The Communication Level of Served Persons with Autism

Summary. In summary, the most typical person with autism described by agencies serving the autistic is 8 years old and had an IQ below 50. Typically the person is able to independently perform basic self care functions, though does not use toys/materials appropriately or engage in activities with age mates. The person exhibits mildly bizarre or destructive behavior on occasion and is able to communicate basic needs but not engage in conversational speech.

Relation of Age and Functioning Level. The question was considered as to whether or not age was in any way related to functioning level. Consequently, chi square analyses were computed on age category by each of the five areas of functioning. Those areas in which significance ($p < 0.5$) was reached are presented in Table 7 - 10. The strongest relationship was found between levels of communication and age (see Table 7) (chi square = 28.11, 2 d.f., $p < 0.0001$). The primary reason for the relationship is that nearly 80% of the 0 - 5 year olds were considered

Table 7

Age Groups

Count Row Pct Col Pct Tot Pct	0 - 5	6 - 12	13 - 21	21 +	Row Total
Low	19 20.4 79.2 7.9	31 33.3 25.6 12.9	34 36.6 44.7 14.1	9 9.7 45.0 3.7	93 38.6
Medium	5 4.3 20.8 2.1	72 62.1 59.5 29.9	31 26.7 40.8 12.9	8 6.9 40.0 3.3	116 48.1
High	0 0.0 0.0 0.0	18 56.3 14.9 7.5	11 34.4 14.5 4.6	3 9.4 15.0 1.2	32 13.3
Column Total	24 10.0	121 50.2	76 31.5	20 8.3	241 100.0

A Chi Square Analysis of the Relationships between Communication Level and Age of Persons with Autism

to be mute or lack communicative speech, as compared to less than one-half of all other age groups being so considered. In addition, the 6 - 12 year old group was less likely than the other age group to be considered mute, and more frequently rated as being able to communicate basic needs

Table 8

Age Groups

Self Care Level	Count Row Pct Col Pct Tot Pct	0 - 5	6 - 12	13 - 21	21 +	Row Total
Low		11 23.9 45.8 4.6	17 37.0 14.0 7.1	34 30.4 18.4 5.8	4 8.7 20.0 1.7	[illegible] 19.1
Medium		9 10.5 37.5 3.7	52 60.5 43.0 21.6	21 24.4 27.6 8.7	4 4.7 20.0 1.7	86 35.7
High		4 3.7 16.7 1.7	52 47.7 43.0 21.6	41 37.6 53.9 17.0	12 11.0 60.0 5.0	109 45.2
Column Total		24 10.0	121 50.2	76 31.5	20 8.3	241 100.0

A Chi Square Analysis of the Relationship Between Self Care Level and Age of Persons with Autism

Table 9

Age Groups

Behavior Level	Count Row Pct Col Pct Tot Pct	0 - 5	6 - 12	13 - 21	21 +	Row Total
		7 8.9 29.2 2.9	26 32.9 21.5 10.8	39 49.4 51.3 16.2	7 8.9 35.0 2.9	79 32.8
		16 11.7 66.7 6.6	80 58.4 66.1 33.2	29 21.2 38.2 12.0	12 8.8 60.0 5.0	137 56.8
		1 4.0 4.2 0.4	15 60.0 12.4 6.2	8 32.0 10.5 3.3	1 4.0 5.0 0.4	25 10.4
Column Total		24 10.0	121 50.2	76 31.5	20 8.3	241 100.0

A Chi Square Analysis of the Relationship Between Behavior Level and Age in Persons with Autism

than either the younger, and, though to a lesser extent, the older age groups.

Both the areas of self care and behavior were also related to age (chi square = 21.92, 2 d.f., $p < 0.0001$) (see Tables 8 and 9). In terms of self care the youngest age (0 - 5 years) was more frequently considered unable to feed, dress and toilet themselves, and conversely less likely to be considered capable of independently performing these functions. Behaviorally it is the older population, particularly the 13 - 21 year olds who were more frequently rated low, that is, as exhibiting a preponderance of severe, destructive and stereotypic behavior. All of the age groups were fairly comparable in the presence or absence of bizarre or destructive behaviors with between 88 to 96% of all age groups exhibiting such behaviors. The 13 - 21 age group and to a lesser extent the above age group exhibit such behavior more frequently and to a more severe extent.

Very few of the entire population were considered to have appropriate social skills such as interpersonal and play skills (only 6.6% of the sample - see Table 10). Those few, however, came exclusively from the school age population (6 - 21), with none of the younger or older being so

Table 10

Age Groups

Count Row Pct Col Pct Tot Pct	0 - 5	6 - 12	13 - 21	21 +	Row Total
	20 14.6 83.3 8.3	58 42.3 47.9 24.1	46 33.6 60.5 19.1	13 9.5 65.0 5.4	137 56.7
	4 4.5 16.7 1.7	54 61.4 44.6 22.4	23 26.1 30.3 9.5	7 8.0 35.0 2.9	88 36.5
	0 0.0 0.0 0.0	9 56.3 7.4 3.7	7 43.8 9.2 2.9	0 0.0 0.0 0.0	16 6.6
Column Total	24 10.0	121 50.2	76 31.5	20 8.3	241 100.0

A Chi Square Analysis of the Relationship Between Social Level and Age in Persons with Autism

rated. The youngest age group was most frequently rated low as compared to other age groups, that is, as using toys inappropriately and engaging in

solitary activities.

Summary. In summary, there was no significant relationship between age and IQ. As compared to other age groups the youngest age group tended to be most frequently rated low in the areas of self-care, social, and communication abilities. Conversely, the older groups, especially the 13 - 21 year olds, were rated low in behavior as compared to ratings for the other age groups.

Relation of the Type of Service Provider and Characteristics of Persons with Autism. The question was next asked whether there were differences between those children served in public schools as compared to all other types of service providers. As expected, age is significantly different in the public schools as they do not provide services to the over 21 age population.

In addition, the intellectual functioning level of students enrolled in public schools was considered to be significantly different than ratings for autistic persons served in all types of agencies. Public school served students were more likely to be considered to have an IQ above 70 than were persons in other agencies. Conversely public school students were less likely to be rated as having IQ below 50 than were persons in other agencies. For persons in state operated institutions, 82.5% were considered to have an IQ below 50, as compared to 50% in public schools and 42.4% in private non-profit programs. Conversely only 3.2% of autistic persons in state institutions were rated with IQs above 70, compared to 21.2% of public school students and 8.5% served in the private sector.

In the other areas of functioning, that is, self care, social, communication, and behavior, no significant differences were found between public schools and all other agency ratings of persons with autism.

Relation of Type of Program and Characteristics of Persons with Autism. Of the persons identified as served by agencies, 100 were in residential programs and 152 were in day programs. Table 11 presents a comparison of percentages, adjusted for missing cases, for the levels of functioning in five areas. The most substantial difference between persons in day versus persons in residential programs in intellectual functioning levels. Persons in residential programs were all rated more frequently as having IQs below 50 than were persons in day programs (72.3% versus 47.6%). Conversely, persons in day programs are more likely to be rated as high in intelligence (IQ above 70) than are all persons in residential programs (19.7% versus 3.2%). In no other areas were there significant differences in functioning level between persons in day versus residential programs. That is, no differences were found in functioning level in self care, social, behavior, or communication.

Table 11

Percentages of Autistic Persons Reported by the Descriptive Survey: Functioning Levels x Day vs. Residential

Level of Functioning	Functional Areas									
	Intelligence		Self Care		Social		Behavior		Communication	
	Day	Res.	Day	Res.	Day	Res.	Day	Res.	Day	Res.
Low	47.6	72.3	16.7	22.9	53.3	64.6	31.5	35.4	39.3	40.6
Medium	32.7	24.5	34.7	36.5	36.7	34.4	55.0	58.3	44.7	50.0
High	19.7	3.2	48.7	40.6	10.0	1.0	13.4	6.3	16.0	9.4
N	147	94	150	96	150	96	149	96	150	96

Services Provided

Public School Programs. Throughout the Commonwealth the project identified 6 public school programs who indicated that they provide services specifically designed for students with autism. Two programs were identified, though full descriptive information was not obtained, for Richmond City and the Southeast Center for Educational Programming (SECEP). Richmond City currently serves four autistic students in one separate elementary class. SECEP is a regional program (serving Chesapeake, Norfolk, Portsmouth, Virginia Beach, Suffolk, Isle of Wight, Southampton, and Franklin counties) and currently has two autistic students enrolled. Full descriptive information was obtained from Fairfax County Public Schools, Stafford County Regional Program, Virginia Beach City Public Schools, and Franklin County Public Schools. Table 12 presents a number of relevant characteristics of these programs. Fairfax County provides separate classes in regular public school buildings for a total of 20 autistic students 5 - 12 years of age and 16 students 13 - 21 years of age. The Stafford County Regional Program serves two students below 6 years of age, five between 6 - 12 years, and one 13 year old in two classrooms also in a regular public school building. Three students are on the waiting list for the program which has a capacity of 10. Virginia Beach City has a separate special education building with one class of 8 designated for multiply handicapped and autistic students. In addition, nine other students with characteristics of autism are served in special education classes with students having other disabilities. Franklin County currently serves 3 autistic students in a special class. All four of the public school programs are providing services 5 to 6 hours per day for 180 days per year.

Table 12

Public School Divisions Indicating They Provide Services Uniquely Designed for Students with Autism

Division	Characteristics			
	# Served	Ages Served	# Waiting	Capacity
Fairfax County	36	5 - 21	0	40
Stafford County Regional Program (Caroline, King George, Spotsylvania, and Fredericksburg City)	8	2½ - 15	3	10
Virginia Beach City	17	2 - 21	0	8
Franklin County	3	2 - 21	0	12

In addition to the above 4 divisions, Descriptive Surveys were completed by 22 other public school programs. These divisions provide services to autistic students in classes designated for students having other types of disabilities, most typically multiply handicapped, mentally retarded or emotionally disturbed students. Insofar as students might be excluded from these programs, it typically would be due to a preponderance of destructive or bizarre behaviors.

State Institutions. In addition to public school operated programs, descriptive information was obtained from 5 programs operated by the State Department of Mental Health and Mental Retardation. See Table 13.

Table 13

Programs Operated by the State Department of Mental Health and Mental Retardation Providing Services for Persons with Autism

Facility	Characteristics			
	# Autistic Served	Ages	Waiting List	Capacity
DeJarnette	13	2 - 14	2	15
Eastern State	12	7 - 14	2	10

Table 13 (continued)

Facility	Characteristics			
	# Autistic Served	Ages	Waiting List	Capacity
Western State	9	14 - aged	3	80
NVTC	23	0 - 60	2	285*
SWVTC	6	0 - 60	0	223*

*Training centers are designed for the retarded, some of whom may also be autistic.

DeJarnette Center for Human Development, Eastern State Hospital Children's Unit, and Western State Hospital (School and Living Skills Program) together currently provide services for 34 persons with autism and have a capacity for 7 more persons. Two of the state training centers, the Northern Virginia Training Center and the Southwestern Virginia Training Center, designed for the retarded, indicated they currently serve some persons also identified as autistic. The capacity figures of the two training centers would be misleading if viewed as capacity for autistic persons for these figures represent the capacity of the total facility. All of the programs in state institutions are residential, full year programs.

Private Non-Profit Programs. The project has identified four private, non-profit programs designed to serve persons with autism as well as persons having other handicaps. These programs include Grafton School (a residential special education program), the School for Contemporary Education (day special education and specialized foster care programs), Children's Achievement Center (day special education programs), and St. Joseph's Villa Respite Care Program. Together these programs are serving 51 autistic persons. (See Table 14). Children's Achievement Center accepts less severely impaired students excluding those who are unable to perform basic self care functions, have no social relationships, are excessively aggressive or bizarre, or who are not able to communicate basic needs. The other three programs accept more severely impaired persons.

Table 14

Private Non-Profit Programs Designed to Serve Persons with Autism

Facility	Characteristics			
	# Autistic	Ages	Waiting List	Capacity
Grafton School	23	2 - 14	6	21
School for Contemporary Education	20	5 - 21	0	20

Table 14 (continued)

Facility	Characteristics			
	# Autistic	Ages	Waiting List	Capacity
Children's Achievement Center	2	6 - 16	0	35
St. Joseph's Villa and Respite Care	6	2 - 21	0	6

Finally, there are a number of private facilities designed primarily for retarded persons who also currently are serving 1 or 3 persons with autism, though frequently indicating that these persons are inappropriately placed. Included are a headstart program, a vocational program, a day program operated by a local ARC (see Table 15).

Table 15

Private, Non-Profit Programs Designed for the Mentally Retarded, Currently Serving Persons with Autism

Facility	Characteristics		
	# Autistic	Ages	Waiting List
People, Inc.	1	3 - 5	0
Charlottesville - Albermarle ARC	1	-	0
WC Ham Learning Center, Inc.	2	-	0
Sarah Bonwell Hudgins Regional Center Education and Development School	2	2 - aged	0
Innisfree Village	2	-	1
Zuni Presbyterian Training Center	2	16 - 22	0

The following description of services offered to people with autism includes, therefore, information provided from 26 public school programs, 5 programs operated by the State Department of Mental Health and Mental Retardation, and 10 private non-profit facilities. The frequency and percentage responses made by these 41 facilities are presented in Table 16. Data are also presented separately for the three subgroups of the 41 total respondents (public schools, mental health, and private non-profit facilities).

Table 16

The Frequency and Percentage Responses Made By 41 Facilities to the Descriptive Survey

Service	Type of Service Provider							
	Total N=41		Public School N=26		State Inst. N=5		Private N=10	
	F	%	F	%	F	%	F	%
I. IDENTIFICATION								
1. Child Find	22	54	22	85	0	0	0	0
2. Diagnosis	21	51	15	58	3	60	3	30
3. Evaluation	38	93	24	92	5	100	9	90
TOTAL $\bar{x}$ =		66		78		80		60
II. EDUCATION, TRAINING OR TREATMENT/ GROWTH SERVICES								
a. Language Development								
1. language training	36	88	26	100	5	100	5	50
2. speech therapy	34	83	25	96	5	100	4	40
3. sign language	26	63	17	65	5	100	4	40
4. total communication system	20	49	13	50	4	80	3	30
5. other non-verbal language systems	19	46	11	43	3	60	5	50
TOTAL $\bar{x}$ =		66		71		88		42
b. Socialization								
1. play skills	37	90	25	96	5	100	7	70
2. peer interaction	40	98	26	100	5	100	9	90
3. interaction w/authority	39	95	25	96	5	100	9	90
4. group interaction	39	95	26	100	5	100	9	90
5. emotional expression	35	85	22	85	5	100	8	80
6. use of leisure time	27	66	19	73	4	80	7	70
7. use of community resources	30	73	19	73	4	80	7	70
8. money management	27	66	17	65	3	60	7	70
9. use of public transportation	14	34	9	35	2	40	3	30
10. sex education	17	41	9	35	3	60	5	50
11. planned experiences with non-handicapped individuals	27	66	20	77	2	40	5	50
TOTAL $\bar{x}$ =		74		76		78		69
c. Personal Independent Skills								
1. grooming	36	88	24	92	5	100	7	70
2. hygiene	37	90	24	92	5	100	8	80
3. housekeeping	28	68	19	73	3	60	6	60
4. care of personal items	32	78	23	89	2	40	7	70
5. independent living	24	58	16	62	2	40	6	60
TOTAL $\bar{x}$ =		76		82		68		68
d. Preacademics	35	85	25	96	4	80	6	60

Table 16 (continued)

Service	Type of Service Provider							
	Total N=41		Public School N=26		State Inst. N=5		Private N=10	
	F	%	F	%	F	%	F	%
e. Academic Instruction								
1. reading	29	71	23	89	2	40	4	40
2. language arts	29	71	23	89	2	40	4	40
3. math	21	76	24	92	2	40	5	50
4. social studies	22	54	20	77	0	0	2	20
5. science	24	59	20	77	0	0	4	40
6. physical education	35	85	22	85	5	100	8	80
TOTAL $\bar{x}$ =		69		85		37		45
f. Specific programming to remediate maladaptive behaviors	33	81	21	81	5	100	7	70
g. Prevocational Instruction	28	68	18	69	5	100	5	50
h. Vocational Instruction	18	44	13	50	1	20	4	40
i. Expressive Development								
1. dance	14	34	9	35	1	20	4	40
2. music	32	78	24	92	4	80	4	40
3. art	34	83	23	89	5	100	6	60
TOTAL $\bar{x}$ =		65		72		67		47
TOTAL $\bar{x}$ =		71		79		69		47
III. RELATED SUPPORT SERVICES								
a. Transportation	36	88	25	96	3	60	8	80
b. Recreation	22	54	10	39	5	100	7	70
c. Counseling	30	73	19	73	4	80	7	70
d. Psychotherapy	7	17	4	15	1	20	2	20
e. Psychiatric consultation	10	24	10	39	5	100	4	40
f. Psychological consultation	29	71	19	73	5	100	5	50
g. Physical or occupational therapy	25	61	19	73	3	60	3	30
h. Speech pathology	35	85	26	100	4	80	5	50
i. Social work	29	71	17	65	5	100	7	70
j. Audiological	29	71	22	85	3	60	4	40
k. Health/medical	11	27	20	77	5	100	4	40
l. Dental	17	42	9	35	4	80	4	40
m. Music, dance or art therapy	13	32	8	31	2	40	3	30
n. Adaptive physical education	24	59	14	54	4	80	6	60
o. Nutritional/dietary	11	27	5	19	3	60	3	30
TOTAL $\bar{x}$ =		54		58		75		48
IV. FAMILY SERVICES								
a. Communication	38	54	13	50	5	100	4	40
b. Training	22	54	13	50	5	100	4	40
c. Counseling	16	39	12	46	2	40	4	40
d. Respite	5	12	1	4	3	60	1	10
e. Support								
1. Regular group meetings	13	31	6	23	2	40	5	50
2. Parent - parent meetings	17	42	11	42	1	20	5	50
f. Advocacy	31	76	20	77	4	80	7	70
TOTAL $\bar{x}$ =		50		48		63		50

Table 16 (continued)

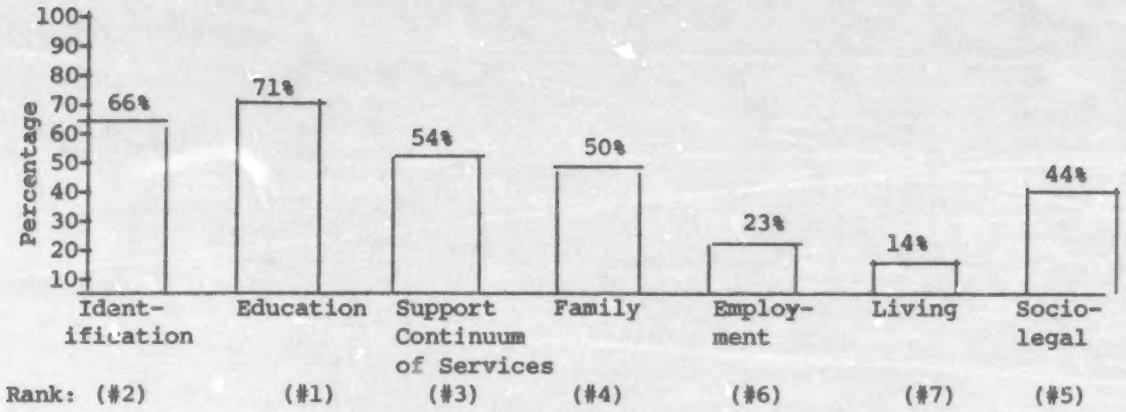
Service	Type of Service Provider							
	Total N=41		Public School N=26		State Inst. N=5		Private N=10	
	F	%	F	%	F	%	F	%
V. EMPLOYMENT SERVICES								
a. Sheltered employment	15	37	10	39	1	20	4	40
b. Supervised/subsidized	5	12	4	15	0	0	1	10
c. Vocational rehabilitation	8	20	5	19	0	0	3	30
TOTAL $\bar{x}$ =		23		24		7		27
VI. LIVING SERVICES								
a. Adult day care	6	15	2	8	0	0	4	40
b. Child day care	3	7	1	4	0	0	2	20
c. Transitional living arrangements	0	0	0	0	0	0	0	0
d. Permanent special living arrangements	3	7	0	0	1	20	10	10
e. Residential - children	8	20	1	4	4	80	3	30
f. Residential - adults	5	12	0	0	3	60	2	20
g. Leisure/recreation	14	34	5	19	4	80	5	50
TOTAL $\bar{x}$ =		14		5		34		21
VII. SOCIAL, LEGAL, INFORMATIONAL SERVICES								
a. Protective socio-legal	20	49	12	46	4	80	4	40
b. Follow along	7	17	8	31	1	20	2	20
c. Information	28	68	16	61	4	80	8	80
d. Consultation and training	15	37	10	39	2	40	3	30
e. Follow-up	20	49	11	42	4	80	5	50
TOTAL $\bar{x}$ =		44		44		60		44

Missing responses, where the respondents failed to indicate either a "yes" or "no" answer to a given service, were scored as "no" responses.

Total Respondents. The responses made by all 41 facility respondents suggest that the availability of the seven major service areas within the continuum of services is as follows, in rank order: #1 - education, #2 - identification, #3 - support, #4 - family, #5 - sociolegal - informational, #6 - employment, and #7 - living services (see Figure 15).

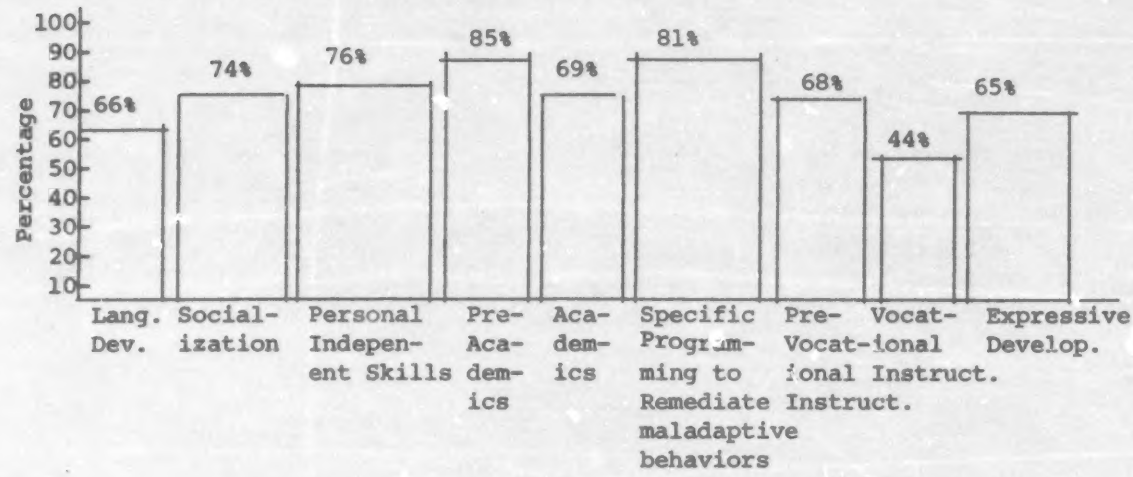
Education, Training or Treatment Growth Services, the service most frequently offered by respondents (71%) consists of a number of component services. The availability of the component education services is shown in Figure 16. As shown by the data, the most available education services appears to be preacademics (85%) and specific programming to remediate maladaptive behaviors (81%), followed by personal independent skills (76%) and socialization (74%). Over half of the respondents indicated that academics (69%), prevocational instruction (68%), language development (66%) and expressive development (65%) services are offered. Vocational instruction was offered by the fewest respondents (44%).

Figure 15



The Availability of Seven Major Services from the Continuum of Services by All Respondents (N=41)

Figure 16



The Availability of Component Education, Training or Treatment/Growth Services

The service offered by the next largest number of facilities, and ranked second, is identification services (66%). Identification services are comprised of three component services; child find (54%) and diagnostic services (51%) are offered by slightly over one-half of the respondents while evaluation activities are offered by the majority of the respondents (93%).

Related support services (54%) were ranked third in order of availability and consisted of 15 component services. Of the component services, transportation (88%) and speech pathology (85%) are reported offered most frequently, ranging to psychotherapy (17%) which is reported offered least frequently.

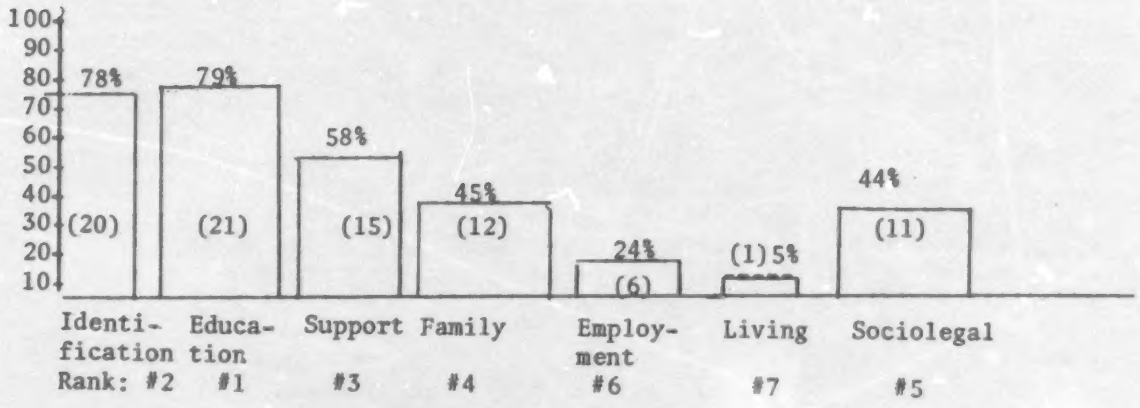
Offered by one-half of the respondents, ranked fourth, family services appear most likely to consist of communication (93%) and advocacy (76%) services, while respite (12%) services are least likely to be offered. Nearly one-half of the respondents also offer social, legal and informational services (44%). Of the component services, protective socio-legal (49%) and follow-up (49%) services are most frequently available, while follow along (17%) services are the least frequently available services.

Employment (23%) and living (14%) services ranked sixth and seventh respectively, are offered by the fewest number of responding facilities. Of the component employment services, sheltered employment (37%) is offered more frequently than either vocational rehabilitation (20%) or supervised/subsidized employment (12%) services. With regard to living services, transitional living arrangements are not reported as being offered by a respondent. Child day care (7%) and permanent special living arrangements (7%) also appear to be rarely available. Within the area of living services, leisure/recreation (34%) are residential living for children (20%) appear to be available in the greatest frequency.

Subgroups of Respondents. The results were next examined to determine whether three subgroups of respondents, that is, public schools, state institutions and private, non-profit facilities, might reveal differing patterns of availability of services. Global differences among the three subgroups seven major service areas are described next.

Public school respondents, (twenty-six respondents or 63% of the total) comprised a subgroup serving 124 or almost one-half of the persons being served by all of the respondents as a whole. As expected, the profile of availability of services provided by public schools resembles closely the profile of services offered by the whole group as shown in Figure 17. Generally speaking, public schools appear to offer identification

Figure 17

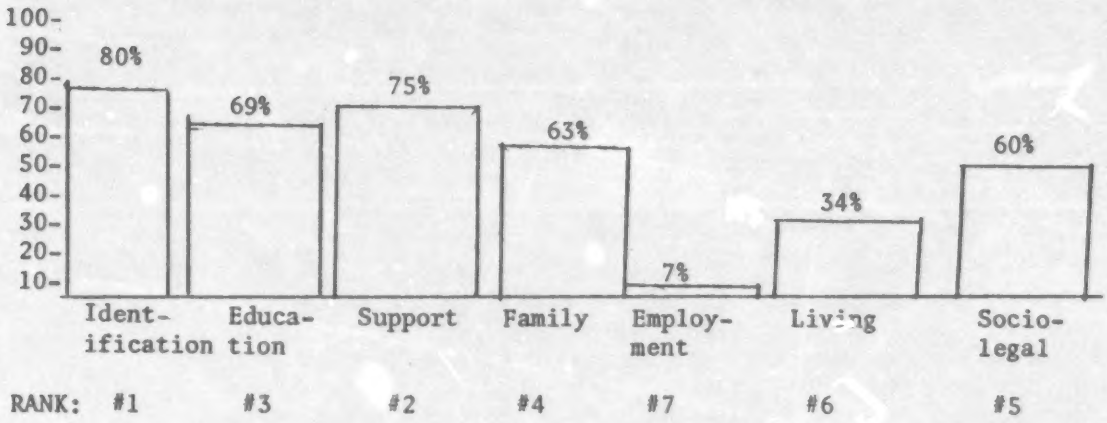


The Availability of Seven Major Services from the Continuum of Services by Public Schools (N=26)

(78%) and education (79%) services more frequently than the group taken as a whole (66% abd 71%, respectively). Support, family, employment and socio-legal-information services are offered as frequently as the whole group. However, in the area of living services, public schools offer services less frequently than all of the facilities combined (5% versus 14%).

The state institutions comprising this subgroup were five and included Eastern State Hospital, Western State Hosptial, the DeJarnette Center for Human Development, Northern Virginia Training Center and Southwestern Virginia Training Center. Although the five facilities represented only 12% of the respondents, the 63 persons served actually represent one-fourth (25%) of the total population served by all 41 responding facilities. The services offered by state institutions differ in a number of ways from the group of all respondents as shown in Figure 18.

Figure 18



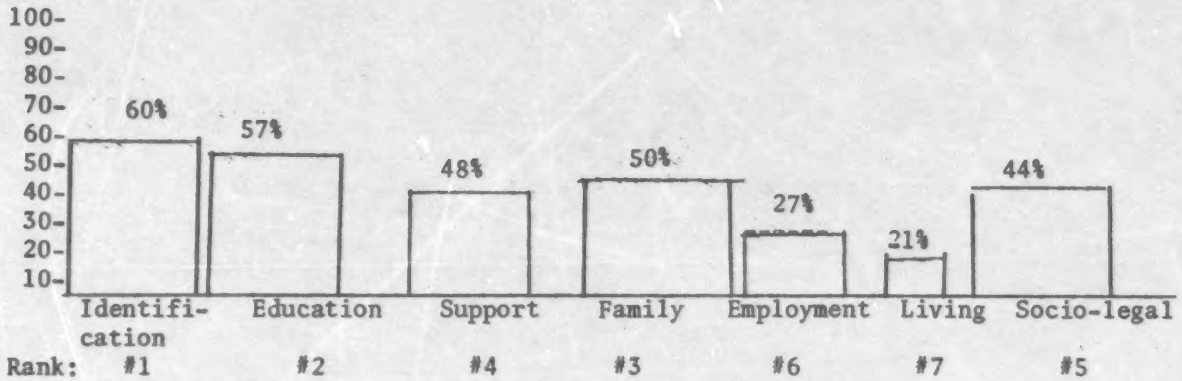
The Availability of Seven Major Services from the Continuum of Services by State Institution Respondents

Perhaps one of the more immediately noticeable differences is that within state institutions the first and second ranked services are identification (80%) and support (75%) services; education services, which are ranked first for the majority of facilities, is ranked third (71%) in availability by mental health facilities. In terms of absolute numbers, mental health facilities appear to offer a greater percentage of the component services available in five of the seven major areas: identification, support, family, living and social-legal-information services. Only in the area of employment services (7%) do the mental health facilities report providing fewer services than reported by the group as a whole (23%).

The ten private, non-profit respondents (24% of the total group) of facilities include the Learning Center, Charlottesville-Albemarle ARC, People Incorporated Head Start, Children's Achievement Center, and Grafton School, and together provide services to 72 persons with autism (28% of the served population). The profile of services offered by private respondents (see Figure 19) seems to occupy a position midway between the profiles exhibited by public school and state institution respondents. Thus, like state institutions, identification (60%) and family (50%) services are

ranked first and third, education (57%) services are ranked second. The percentages of services offered, while lower than the group as a whole, do not appear significantly different with the exception, possibly, of education services (57% versus 71%). Living services (21%), by contrast, appear to be offered at a somewhat higher rate from the group as a whole (14%).

Figure 19



Continuum of Services

The Availability of Seven Major Services from the Continuum of Services by Private, Non-Profit Respondents

Summary. In summary, the responses of 41 facilities regarding the availability of 74 services in seven major areas revealed that education, training or treatment/growth services (71%) are the most available services in Virginia. Identification (66%), support (54%) and family (50%) services are offered by over one-half of the facilities. Employment (23%) and living (14%) services are the least frequently offered services.

Regarding differences of services among public schools, state institutions, and private non-private agencies, public schools are to engage in child find activity and to provide academic instruction. Regarding child find, only public school programs reported engaging in this activity. Even so, for the public schools reporting, only 85% indicated engaging in this mandated activity. As would be expected, all of the academic areas with the exception of physical education (reading, language arts, math, social studies, and science) are reportedly offered by a significantly higher percentage of public schools than by the other service providers. On the other hand, public school programs are significantly less likely than other providers to provide recreation as a related service or leisure and recreational services under the category of living services.

Regarding programs operated by state institutions, that system provides more residential services for both children and adults than provided elsewhere. Most adult day care (Living Services) is provided by the private sector. In addition the private sector is significantly less likely to provide the Related Support Services of speech therapy,

psychological consultation, physical or occupational therapy, speech pathology, or health. It must be remembered, however, that the facilities comprising private sector respondents include many diverse types of programs.

Staff-to-Client Ratios and Cost of Services. An analysis of staff-to-client ratios within the facilities was attempted. Results indicated that due to the imprecise and varied reporting methods used by respondents, no definitive statements can be made concerning staff-to-client ratios in Virginia. In addition, it was not possible to gather accurate and meaningful cost data regarding program services.

Contact with Non-handicapped persons. Programs were asked to indicate in narrative form the degree and nature of contact persons have with non-handicapped persons. Thirty-two programs responded to this question and their responses were rated as "high", "medium", or "low" according to the relative criteria; see Table 17. In the majority of programs (59.4%), autistic persons have little contact with non-handicapped persons. Only 9.4% of the programs described structured plans for meaningful experiences with non-handicapped persons. There were no significant differences between program type and degree of contact with the non-handicapped persons.

Table 17

Degree of Contact with Non-Handicapped by Persons with Autism

Degree of contact	Facility Type			
	State Institutions	Public Schools	Private	Total
High	0	1	2	3 (9.4%)
Medium	3	6	1	10 (31.3%)
Low	1	13	5	19 (59.4%)

Service Needs. The final section of the Descriptive Survey pertained to service needs. With regard to program development needs, facilities reported a significant need for assistance in several areas. Due to the fact that some facilities gave incomplete information, the following percentages have been adjusted. Areas where facilities indicating needing assistance include: training current staff (71%), securing adequate funding (70%), program planning for education, training or treatment (72%), and securing appropriate curriculum materials (69%). Only two areas were reported by agencies as not needing assistance; those were program planning for living services (58%) and program planning for social, legal and information services (63%). Agency responses to the remaining areas do not indicate a clear directional response, that is, equally as many agencies indicated a need for assistance as indicated no need for assistance

in the area. These items are the following: securing appropriately trained staff (54%), program planning for identification (54%) and program planning for employment services (50%).

Regarding service needs for their autistic clients upon terminating from the program, 17 facilities responded. Most frequently noted were needs for living services and employment services. The need for permanent residential services was noted by 9 facilities, with 6 indicating a need for vocational training, 5 for sheltered employment, and 5 for day care of leisure activities. An additional 5 facilities indicated need for special education, specifically noting needs for behavior management and speech or language training for their terminated clients. Finally, several facilities indicated a need for Family Services with 4 specifically noting respite care. Of the 17 respondents, therefore, 59% indicated future needs for Living Services, 53% for Employment Services, 41% for Special Education and Related Services, and 29% for Family Services.

Survey of Institutions of Higher Education

The survey, sent to both the Department of Psychology and the Department of Special Education at 38 colleges and universities in Virginia, was returned by 81.5% of the institutions of higher education. See Appendix Q for a complete listing of colleges and universities and their responses to the Survey of Institutions of Higher Education.

The results of the survey reveal that no departments within any college/university in Virginia currently offer a course in autism. However, 23 of the responding institutions (60.5%) indicated that a course including study of autism is offered; the course offering appears to occur equally in the departments of psychology (50.9%) and special education (49.1%).

Evaluation

The results of facility evaluations were analyzed by collapsing 838 individual items (independent variables) into ten major functional areas and sub-areas; for example, all items related to the major area of "General Facility Administration" were analyzed according to five component sub-areas. See Appendix G for a listing of the variables on the Evaluation Form. The items within each sub-area were evaluated by a series of ten statements categorized into three major dependent variables - "status" (degree of implementation), "evaluation" (level of acceptability) and "importance" (value of potential needed improvement to facility respondents). In order to determine the overall degree of implementation plus level of acceptability plus importance, the responses to each item were assigned a "priority quotient" (P.Q.) based on the following formula:

$$P.Q. = (1 - \%\ \text{fully implemented status}) + (\%\ \text{needs improvement}) + (\%\ \text{critical importance})$$

The purpose of the priority quotient, thus, is to signal which services are least developed or implemented, most needing improvement and most critical in importance to evaluators within each facility. The probability that particular services represent significant priorities was determined

by calculating the standard deviation of each priority quotient. Priority Quotients greater than one standard deviation over the mean (+1 S.D. or over 85%) are considered to indicate a "high priority" need while priority quotients ranging from 0 to 1 S.D. (50 - 84%) represent a "priority" need. See Appendix R for a complete listing of service variables together with their respective Priority Quotients. A final note is that additional items within sub-areas of "education" were analyzed in order to allow comparison to the continuum of services used in both the Parent Survey and the Descriptive Survey.

The data resulting from facility evaluations suggest that the major service areas needing priority attention are Education, including language training, socialization, and personal independence skills; Related support services; and Living services. See Table 18 for a listing of all high priority and priority services according to major service area.

Table 18

High Priority and Priority Services Based
on Facility Evaluations
(N = 12)

Major Service Area	High Priority*	Priority**
General Facility Administration	None	Program Evaluation
Individual Client Planning	Annual Plan for Individual Clients	Short term objectives
Observation of Services	Short term objectives	Service Environment
Identification	Diagnosis	
Education	Sign Language	Other non-verbal communication system
	Total communication	Group Interaction
	Use of Community Resources	Emotional Expression
	Use of public transportation	Use of leisure time
	Planned experience with non-handicapped	Grooming

Table 18 (continued)

Major Service Area	High Priority*	Priority**
		Hygiene
		Reading
		Specific programming to remediate maladaptive behaviors
		Vocational Instruction
Related Support Services	Social Work	Transportation
		Recreation
		Speech Pathology/ Language training
		Audiological
		Nutritional/dietary Evaluation
Family Services	Respite	Parent Training
		Support
Employment Services	None	None
Living Services	Child Day Care	Residential for Children
		Residential for Adults
		Leisure/Recreational Resources

* = + 1 S.D. or over 85%
** = 0 to 1 S.D. or 50% - 84%

General Facility Administration

Administration services were not found to exhibit high priority needs; however, program evaluation was designated as a priority area. Program evaluation was characterized by having a high percentage of need (42%) for programs with periodic evaluations of service effectiveness.

Individual Client Planning

In the area of Individual Client Planning, the provision of annual plans for individual clients was considered a high priority area for needed improvement. Components of this service requiring improvement include the need to specify more functional skills for the client and to periodically evaluate client progress. Additionally, the writing of short-term objectives constituted a priority area; here, concerns revolved around the need to use the community as a resource for programming and to insure the generalization of skills to other environments.

Observation of Services

Observation of Services in which evaluation of a subset of services by study staff as opposed to facility representatives, revealed that short-term objectives were a high priority item. The chief concerns were that data based programming as well as implementation consistent with written plans occured at a low frequency. Other facets of the service environment were also perceived as priority items, namely, the coordination of objectives and the provision for concrete follow-up plans prior to exit from a program. With the exception of the external observation of services, judgments regarding all of the remaining items were made by staff of the facilities themselves. Consequently subsequent mention of "evaluative comments" refer to comments made by individuals employed by the facility who were interviewed by project personnel.

Identification Services

With regard to Identification Services, diagnosis was seen as a high priority service. Specifically, facility representatives responded that the use of a multi-disciplinary approach, of a thorough parent interview, and of written criteria for the determination of a diagnosis were frequently not offered.

Education Services

The area of Education Services, as mentioned earlier, revealed a high number of services requiring high priority attention, including sign language, total communication, use of the community, transportation, sex education, and planned experiences with non-handicapped persons. With regard to sign language and total communication, the services were viewed as being of critical importance and as being provided for less than a sufficient amount of time each week. Education services believed to represent priority items included language training in other non-verbal communication systems, socialization by group interaction, emotional expression and use of leisure time, self care, grooming,

development in hygiene, reading, specific programming to remediate maladaptive behaviors, and vocational instruction.

Many questions were asked about the use of specific programming for maladaptive behaviors. The evaluations indicated that concerns related primarily to the critical importance of specifying methods used and the designation of a person responsible for the implementation of the behavior change program. Further, evaluations stressed the need to improve data collection designed to assess program effectiveness as well as to be able to demonstrate through written evidence that positive procedures had been systematically tried and proven ineffective as an antecedent to the use of aversive consequences. Finally, a relatively high percentage of evaluators remarked that there was need for a written policy/procedure for the use of aversive consequences.

The vocational instruction services offered by the facilities earned priority ratings due to a number of reasons. Training methodologies, equipment, and materials need improvement, together with activities appropriate to the developmental ages of the persons being served. Vocational instructional programs lack written assessment data in many cases.

Related Support Services

The service area Related Support Services was second only to Education Services in terms of numbers of services requiring priority attention. Social work, a high priority item, was characterized as having a high percentage of no services in case management, parent contact, liason between program and home, and follow along. Dental services were likewise perceived as high priority services in terms of specialty care, daily oral care and dental hygiene instruction. Several service areas were also identified as priority areas: transportation, recreation, speech pathology, audiology and nutrition/diet.

The responses by evaluators indicated special concern regarding the absence of written procedures for emergency and behavior management; also, the provision of adequate insurance was seen as critically important. Recreation services were rated as having few services geared toward skill training in a range of activities. The components of speech pathology appearing to contribute to a high priority rating were the lack of services for speech therapy specialties (sign language, total communication, and other non-verbal communication systems), generalization training, and consultation for line staff as well as improvements needed in sign language and the number of hours provided on a weekly basis for speech services. Audiological services were judged as requiring priority attention primarily due to the lack of specialized examinations occuring on an annual basis. Finally, nutrition and dietary evaluations were perceived as virtually non-existent.

Family Services

A high priority need for the Family Service of respite care was noted; written plans for staff selection and training, program services and

continuity with other programs were all characterized as unavailable services. Parent training and support services represented priority concerns. Parent training was seen as a combination of not being a frequently offered service, and when offered, needing improvement. Support services frequently lacked procedures for parent orientation, regularly scheduled meetings, providing information about regional services, and for parent to parent activities.

Employment Services

Employment Services were not noted by the presence of priority items; however, few settings evaluated offered employment services.

Living Services

The final major area, Living Services, revealed high priority needs in child day care services. Child day care programs seem to be virtually absent in the state, although the importance of this service is described as critical. High priority services include residential services for children and adults and leisure/recreation activities, primarily due to the absence of these services.

Summary

Services were evaluated as having high priority and priority needs for further development and improvement based on results gained from the use of the Priority Quotient. The majority of direct services exhibiting high priority needs were education and related support services; within these major areas, services related to language and socialization training and social work were frequently indicated. Respite care and child day care were additional direct services that were rated as high priority areas for improvement. No employment services were rated as either high priority or even priority areas due to the fact that so few employment services are offered and, hence, available to be evaluated. Indirect services that were evaluated as being high priority for improvement were annual plans and short term objectives for clients.

V. DISCUSSION

Recommended Operational Definition of Autism

The first objective addressed by the present study was to recommend an operational definition of autism. Following an extensive review of the literature and communication with experts in diagnosis, the NSAC definition was selected. There are several reasons whe the NSAC definition is recommended to be adopted as the state definition of autism: 1.) It is comprehensive and gives a detailed description of the characteristics of autism; 2). The NSAC definition is compatible with the definition found in the DSM III; and 3). The NSAC definition is designed not just for researchers, but also for those providing disgnosis for the purpose of education and treatment. The NSAC definition served as the model from which an abbreviated definition was evolved and which was operationalized in the form of the Autism Checklist. While the constraints of time did not allow a rigorous investigation of the psychometric properties of the checklist, a pilot study was conducted with the checklist to determine whether it was, in fact, a rudimentary reliable, easily used instrument.

The finding of the pilot study of the Autism Checklist was that parents and professionals alike were able to readily complete the instrument. An even more important finding, was the high degree of agreement between parents and professionals regarding the characteristics of the persons with autism. According to the criteria used by the study, 98% of the persons described by the parents on the Autism Checklist were found to be autistic. The results of the Parent Survey, completed by the 118 parents who also completed the Autism Checklist, revealed moreover, that 93% had children who had been independently disgnosed at one time or another as autistic or autitic-like.

It is also important to note that an extremely high percent of all five of the major characteristics noted in the NSAC definition and reflected on the checklist were checked as descriptive of the population. Fully 98% had characteristics noted in four or more areas, and even the least frequently checked area was 92.3%. This high degree of internal consistency lends support to the hypothesis that the five areas are indeed characteristics of autism and therefore to the validity of using the NSAC definition. Thus, the initial impression is that the Autism Checklist represents a promising and accessible instrument to assist in the screening and diagnosis of autistic persons.

The Autism Checklist is not, given our present level of knowledge, appropriate for use as a diagnostic instrument used in isolation. Used for the purposes of screening persons for large scale planning, such as by state or local regions, for program planning within a given facility, or as an instrument as part of a multidisciplinary evaluation of persons suspected of having autism, the Autism Checklist would constitute an effective aid. Indeed, the need for large scale screening to identify persons with autism was clearly portrayed in the results of the study.

It is recommended that the various state agencies in Virginia adopt the NSAC definition contained in Appendix D for use in the Commonwealth of Virginia. It is further recommended that subsequent research be conducted with the Autism Checklist to improve its psychometric properties.

For example, a discriminative analysis evaluation would be useful to determine the degree to which the Autism Checklist discriminates the autistic population from other types of handicapped persons.

Enumeration of Persons with Autism

The task of counting and describing persons with autism in Virginia proved to be a monumental undertaking. Few such studies have been done in the world, and no statewide studies have been attempted in the United States. Further, previous studies of the prevalence of autism or similar handicapping conditions have differed greatly in methodology and results. Some studies, for example, have been concerned with the incidence (the rate of initial occurrence) of a condition, rather than prevalence (rate at which it is currently found, new and old cases) (Lindberg & Putman, 1979). The normal recourse in state plans has been to study regional population figures and to formulate expected prevalence figures, usually 10 - 20 per 10,000.

Obstacles to Enumeration

Interestingly, the obstacles encountered in the enumeration phase of the present study oftentimes proved as instructive as the final results so painfully gleaned. A few words on the "obstacles" met in the attempt to enumerate are in order. As noted in the introduction, few state departments have a centralized data store which specifically notes information about the handicap of autism. Persons with autism may be subsumed under various classifications such as "emotionally disturbed", "mentally retarded", "other health impaired", or just "other". Part of the classification problem leading to the difficulty in data retrieval is, too, the lack of an accepted, statewide definition of autism.

Another obstacle encountered was created indirectly due to the right of confidentiality provided to all persons by service facilities. As a result, the method used in enumerating persons with autism required "middle men", agencies and professionals, to send our request for information to parents of the autistic. The findings of the enumeration phase of the study, thus, are biased by the degree of cooperation received from the contacted agencies and the fact that the person with autism was known by the service agency. In effect, the study identified and counted those persons already diagnosed as autistic. It did not function in a "child-find" capacity in the sense of identifying persons with autism who had not previously been so identified, in most cases.

Enumeration Produced a Small But Known Group

In spite of these obstacles, the question can now be asked, "What do we know about persons with autism in Virginia?" A few conclusions can be drawn but many more guesses must be made. An important consideration to remember is that the study identified only a small fraction of the expected population in Virginia. One suspects tha the persons counted and described probably represent a skewed sample which is not representative of the entire Virginia population. Several clues lead to this conclusion: 1.) the fact that most of the persons identified were already diagnosed

and receiving services, 2.) the disproportionate geographic distribution of the responses, and 3.) the unequal age distribution of the persons identified. What the results of the study do provide, however, it information about a small, but known group of persons in Virginia.

Age of Persons Enumerated

The study obtained information on 118 persons described by parents and 252 persons described by agencies. Fifty-four persons were described by both the agency and the family such that descriptive information was collected on a total of 316 persons with autism. The age distribution of the 316 persons is presented in Table 18 together with the expected age prevalence based on a prevalence of 15 per 10,000. Overall, only 4.1% of the expected autistic population has been identified. In addition, it can be seen that a relatively higher percent of the school aged population have been identified than the non-school age population, particularly the 6 - 12 year olds. These ages also correspond to the availability of services, there being more services for the 6 - 12 year olds. It would appear that it is more likely the autistic will be identified, thus, when services are available. This assumption is further supported by the geographic location of the identified population which tends to cluster around areas that provide more extensive services.

Table 18

Identified versus Expected Number of Autistic Persons by Age Category

Age Category	Virginia Population	Expected Autistic	Identified Autistic	% Identified vs. Expected
0 - 5	537,007	806	35	4.3%
6 - 12	733,007	1,101	150	13.6%
13 - 21	908,813	1,363	92	6.7%
21 +	3,017,499	4,526	33	0.7%
Total	5,197,000	7,796	310	4.1%

*no age was reported for 6 identified autistic people.

Functioning Level of Persons Enumerated

The following is the composite description of the functioning level of the full 316 persons with autism. The percentage responses in terms of the five areas of functioing are presented in Figure 19.

Overall, the majority of persons were found to be functioning with an IQ below 50. Only 18% of the sample had an IQ above 70. Most typically (45%) the autistic persons were considered to be able to independently

perform basic self care skills, although 39% of the persons were considered only partially capable and an additional 16% were unable to feed, dress or toilet themselves. Socially the majority (53%) were considered to use toys or materials inappropriately and to remain isolated. Only 7% of the persons enumerated were considered readily able to approach their peers.

Figure 19

The Functioning Level of 316 Persons with Autism as Reported by their Parents

Level of Functioning	Percentages of Responses in 5 Areas of Functioning				
	IQ N=303	Self Care N=311	Social N=311	Behavior N=310	Communication N=310
Low	53%	16%	53%	29%	35%
Medium	29%	39%	40%	59%	50%
High	18%	45%	7%	12%	15%

Behaviorally 59% of the persons were reported to exhibit intermittent or mildly bizarre or destructive behavior and for only 12% was the absence of such behavior reported. Finally, half (50%) of the persons were considered able to communicate basic needs, 35% were observed to be mute or to lack speech with communicative intent, and only 15% exhibited conversational speech.

It is interesting to note that the two reporting groups, parents and professionals within agencies, yielded generally very similar overall average data. The percent response of these two groups as well as the overlap group of 54 Parent Surveys are presented in Table 19. For all groups the average age was about 8 years.

Table 19

The Percent Response by Parents and Agencies Regarding The Functioning Level of 316 Persons with Autism

Functioning Level	IQ			Self Care			Social			Behavior			Communication		
	P	O	A	P	O	A	P	O	A	P	O	A	P	O	A
Low	31	33	57	6	6	19	42	52	58	20	27	33	20	30	40
Medium	29	44	30	54	57	35	48	42	36	64	62	57	62	64	47

Table 19 (continued)

Functioning Level	IQ			Self Care			Social			Behavior			Communication		
	P	O	A	P	O	A	P	O	A	P	O	A	P	O	A
High	28	23	13	39	38	46	9	6	7	14	12	11	17	11	13
N	114	43	242	117	53	247	116	52	247	116	52	246	116	53	247

P = Total Parent Survey Response
O = Overlap - Those Parent Surveys for persons in a reporting agency
A = Agency Response - Total
(A + P - O = 316)

Agency responses tended to rate IQ below 50 more frequently than parents, including parents in the overlap group, and conversely were less likely to rate IQs above 70. Similarly, more agency ratings were low and fewer were medium in communications, behavior, and social than were parent ratings, with the overlap group falling midway between these two groups. In self care, agencies were more likely to rate low and high, and less likely to rate medium than were parents including parents in the overlap group. Insofar as there is a trend, therefore, it is for the persons rated by agencies to be considered functioning lower than persons rated by their parents. In both cases, however, the predominant ratings were low.

The question remains unanswered at this time whether the reported differences between parent and agency responses are related to perceptions of the respondents or to true differences between the two groups. One point that is clear, however, is that the persons so described fit the clinical impressions of those usually diagnosed as autistic and effectively illustrates the severity of the handicap.

Placement and Distribution of Persons Enumerated

Another similarity in the results obtained from the parent and agent surveys was in regard to the proportion of persons enrolled in day versus residential programs. Both parents and agencies reported that 60% of their children were enrolled in day programs, while 40% were enrolled in residential programs. The overlap group, however, had the opposite rate with 60% of the persons placed in residential facilities.

As might be expected, the majority of low functioning persons are currently placed in residential facilities whereas the higher functioning persons are enrolled in day programs. The critical variables for differential placement were found to be intellectual, self care, behavior and communication abilities. No differences were found between persons placed in day and residential programs based on social abilities, according to parents. Agecny responses, however, indicated that only intelligence level differentiated between persons in day and residential programs.

A final look at the characteristics of persons with autism in Virginia revealed only minor findings. For instance, the ages of persons in the five Health Services Areas were found to be different. That HSA II (Northern Virginia) has a more evenly distributed population in terms of age perhaps reflects the broader range of services available in the area. Again it is apparent that insofar as services are available, the autistic person becomes identified.

Summary

The primary points to be emphasized from the enumeration and description of the population in Virginia are: 1.) a very small percent of the actual population has been identified thus far; 2.) there is the clear suggestion that more persons with autism are identified in geographic areas with more developed services; and 3.) this population is characterized by extremely severe impairment in important areas of functioning.

Description of Services Currently Available in Virginia

Input regarding services was obtained from surveys completed by both parents and agency personnel. The information from the two groups of respondents does not extensively overlap due to the fact that, as previously mentioned, only 54 of the 118 respondents (46%) had children with autism enrolled in facilities which completed Descriptive Surveys. Nearly one-half (43%) of the persons with autism described by their parents attended facilities that did not return a Descriptive Survey (25%), attended a facility outside Virginia (6%), or were not receiving services (12%). Accordingly, the responses by parents and agency personnel regarding services currently offered are reviewed separately.

Current Service Needs

Parental perceptions of services currently offered or not offered are perhaps best understood through inspection of responses to the question "What service does your child presently need?" on the continuum of services presented in the Parent Survey. The most obvious finding was that parents characterized the current service delivery system as deficient in services related to education and support services. This deficiency was noted in spite of the fact the majority of persons studied were of school age. With regard to education, needed services included language training, a variety of social or play skills such as the use of leisure time, use of the community, experiences with non-handicapped individuals, physical education and vocational instruction. Needed services in the area of support include recreation, counseling and psychotherapy, psychological consultation and social work. Training and counseling were also described as needed family services. As a whole, parents did not report current needs for employment or living services, although a number of component services were characterized as future needs: sheltered and supervised employment, vocational rehabilitation, adult day care, and leisure/recreation. When the above 21 years age group of the population was considered separately, however, significant needs were indicated in the areas of supervised/subsidized employment and residential services for adults.

The impressions gained from parent descriptions of their childrens needs from the current service system are several, therefore. Although the majority of respondents are parents of school age children (6 - 12 years old), the desire for education services appears to crystallize around services designed to enhance social and vocational development. Parents also appear to be asking for more services geared toward increasing their own skills in managing or "normalizing" a handicapped family member, typically through a combination of psychological and recreational resources for the family and the autistic family member.

Future Service Needs

Regarding future needs, virtually every service on the continuum was noted. The overall average rate for indicating future needs for all services was 9.1%! Responses ranged from 68.9% (for Education and Training in sign language) to 100% for several services. Over two-thirds of the respondents indicated future needs in every area and there was virtually full agreement on the need for most services. The prioritization method used in the presentation of results needs to be tempered with the understanding that responses above one standard deviation above the mean (designed "x" in Table 3) reflect raw percentages of 98.2% to 100%; whereas responses from 0 to 1 standard deviation above the mean response (designated "0") include raw percents of 91.9% to 98.2%. In real terms, therefore, this type of prioritization is not useful in terms of priorities for recommended action. Such decisions will need to take into account existing services and judgments regarding the most cost effective actions. That virtually all services listed on the continuum are projected as future needs does, however, provide credibility for the validity of the continuum itself. Existing programs may find the continuum of value in determining the comprehensiveness of their services for autistic persons.

Particularly noted by over 98% of the families were projected needs for education and training and socialization, particularly use of leisure time, community resources, and peer interaction, prevocational and vocational instruction, and support services especially including transportation, recreation, speech pathology and language training. Also noted by over 91% of the families were projected needs for evaluation; education and training in language, all areas of socialization, all areas of personal independence skills, academic instruction in math and physical education, specific program in maladaptive behavior, expressive development; support services and counseling, psychological consultation, music, dance and art therapy; family communication and training; all employment services; and living services focused on adult day care and recreational resources.

Level of Satisfaction with Current Services

When queried about their level of satisfaction with current services, parents responded in a positive way about the services received. However, many of the services received were also unsatisfactory to parents. Once again, the same services which were identified as current and future needs were also indicated as unsatisfactory, particularly education and language, socialization, and vocational skills. Related support services were also strongly characterized by lack of satisfaction as were family services.

Summary

In summary, therefore, this small group of families, with children already clearly identified as having autism, the vast majority of whom are enrolled in some services, nonetheless expressed clear current service needs, as well as overwhelming future needs for service. If this represents the views of a sample of the "best" served persons with autism in the state, what needs exist for those currently not even identified?

Current Service System

Specific description of the current service system was also provided by responses to the descriptive survey from public schools, state institutions, and private facilities across the state.

Public Schools. With regard to services provided by public schools, information obtained from a short form sent to all school divisions, information provided on the actual Descriptive Survey, completed by those divisions where there was some indication services were being provided, as well as telephone information from other divisions, indicates that the total number of students recognized by the school divisions as having characteristics similar to those of autism is 217. This number represents a prevalence of only 2 per 10,000 students, a rate indicating that only between 10 and 15% of the autistic school age children have been identified. Only 49 students were specifically reported as diagnosed with autism, a rate of only 0.48 per 10,000 students. It is not surprising, therefore, that relatively few local school divisions report providing services for the autistic or autistic-like student. Indications from all sources are that only 47 divisions (one-third of all divisions) are serving children recognized as having characteristics similar to those of autism. Of those 47 divisions, two-thirds report serving 3 or fewer students with autism.

It is even less likely that public schools consider that they are providing services uniquely designed for autistic students. Most divisions, insofar as services are being provided, serve the autistic in classes primarily designed for the retarded, emotionally disturbed, or multiply handicapped student. Only 6 public school programs (including 2 regional programs) were identified as providing services uniquely designed for the autistic student.

State Institutions. Apart from the scattered services provided by the public schools, the State Department of Mental Health and Mental Retardation operates programs serving a total of 34 children with autism at DeJarnette, Eastern State, and Western State Hospitals. In addition, two training centers (programs for the retarded) report serving 29 persons who also were considered to be autistic. In general the persons served by the state Mental Health and Mental Retardation system were considered to be intellectually functioning at a lower level than those in the public schools or other setting. In all other respects, however, these persons were not considered to be functioning at significantly different levels from those in public or private educational programs.

Private, Non-Profit Facilities. In the private, non-profit sector one major residential and one major day educational program were identified serving a total of 33 autistic students. Eight other private non-profit facilities, most of whom are designed for the retarded, report providing services of various kinds for 1 or 2 autistic persons.

Lack of Integration Among Service Providers. Overall, therefore, there is no comprehensive, integrated system of services for the autistic person. There is no comprehensive system for the identification of such persons (indeed, very few have been so identified). Apart from the few local school divisions, centralized residential services for a few children provided by Mental Health, and a smattering of private programs, services do not exist. No state agency has clear responsibility for this population. The State Department of Education does not recognize autism as a distinct disability and therefore has no program guidelines, no teacher endorsement, encourages no teacher training in higher education, and has no funding reimbursement formula for local school divisions for the disability of autism. It is not surprising, therefore, that few local school divisions can provide adequate services for this population. The State Department of Mental Health and Mental Retardation provides services in isolated, non-integrated residential settings for only a minimal number of persons and these services are designed for the severely intellectually impaired. Only a few facilities in Virginia's relatively large private sector have begun to develop extensive services for this multiple impaired, difficult-to-serve population.

Services Currently Provided

A detailed look at the specifics of the few services that are provided is obtained from the Descriptive Survey. The results of the present report were comprised of data on specific services offered in terms of the percent of facilities out of the total sample providing the service. In order to present the information in a manner that highlights the insufficiency of the extent of services in Virginia, the specific services are discussed in terms of a number of persons potentially receiving the services as determined from the Parent Survey and the Descriptive Survey. The figures were obtained by condensing the numbers of autistic persons served at each facility, together with the services offered by that specific facility. In all, 252 served persons are reported on the 41 Descriptive Surveys. In addition, there were 43[1] autistic persons reported by the families in the Parent Survey who are not included in the Descriptive Survey but who are currently receiving services. Thus, it is possible to estimate specific services for these 43 persons on the basis of the overall percent of the Parent Surveys indicated receiving specific services as presented in Appendix N. This section, therefore, discusses services for all of the persons that the project was able to identify as being served, a total of 295.

Most typically the group of persons served were receiving some type of educational or training and related support services. Throughout the

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[1] The number 43 was derived by taking the total number of Parent Surveys (118) and subtracting the number of persons also described in the Descriptive Survey (54), the number unserved (14), and the number out of state (7).

Commonwealth the project identified only 268 autistic people in facilities providing education and training. Most typically the focus was on socialization, language training, and personal independence skills. See Table 20 for a summary of education and training services.

Table 20

Total Number of Autistic Persons Receiving Educational Services

Age	N	Language	Socialization	Personal Independent Skills	Pre-Academics	Academics	Specific Program Behavior	Pre-Vocational	Vocational	Expressive Development
0 - 5	30	27	27	26	25	26	23	20	9	25
6 - 12	141	119	129	126	124	121	107	97	22	113
13 - 21	86	82	82	81	75	63	75	70	42	71
21 +	27	22	25	24	19	11	19	20	15	22
Unidentified	11	5	5	5	5	5	4	4	4	5
TOTAL	295	265	269	264	248	220	228	211	94	236

The educational areas least offered to the autistic are vocational and pre-vocational training, with only a total of 94 people in the Commonwealth estimated as having access to vocational training.

In terms of related support services, 243 autistic persons were identified as being served by facilities offering these services; see Table 21. Services most typically offered for the persons identified are speech pathology or language training, transportation, physical or occupational therapy, and adaptive physical education. Least frequently offered are psychotherapy and nutritional counseling.

Regarding identification services, only the public schools engage in "child find". Consequently there is no active process to identify autistic persons above 21 years of age. In addition, child find activity that does occur is not necessarily specifically related to autism.

Of the 295 persons identified as served, 254 were in facilities indicating that they provided family services, most typically ongoing communication with the families. Seldom provided services were respite care and family counseling. In terms of living services, 111 autistic persons receive leisure or recreational services. However, only 5 persons

were indicated in adult day care, and 9 in child day care. Only 2 persons over age 21 years are in permanent living arrangements and those are living in a private facility designed for the retarded. Throughout the Commonwealth only 69 autistic persons were identified receiving services from facilities providing employment services.

Table 21

Total Number of Autistic Persons
Receiving Support Services

Age	Transportation	Recreation	Counseling	Psychotherapy	Psychiatric Cons.	Psychological Consultation	Physical or Occupational Therapy	Speech Pathology	Social Work	Audiological	Health-medical	Dental	Music, Dance, Art Therapy	Adaptive Physical Educ.	Nutritional Counseling
0 - 5	22	10	11	6	15	20	20	26	17	18	17	7	17	20	8
6 - 12	94	87	70	27	65	89	99	115	77	94	60	47	55	93	36
13 - 21	73	56	46	19	52	48	69	74	52	68	64	40	31	65	31
21 +	23	5	20	11	19	20	13	16	20	14	23	22	18	23	17
Unidentified	5	5	4	0	1	4	4	5	3	5	1	1	0	1	0
TOTAL	217	163	151	63	152	180	205	236	169	199	165	117	121	201	92

Current Service System in Relation to Expected Prevalence

The overall picture of estimated services for the autistic in comparison to the estimated number of autistic persons is presented in Table 23; the table also analyzes the information by age group. As can be seen, only approximately 3.7% of the 0 - 5 year olds are estimated as being served. The 6 - 12 year old group is the most identified and served and yet it is estimated that only 12% to 13% of this age is receiving services. Overall it is estimated that between 6% and 7% of the 13 to 21 year olds are being served, though with few employment, living or social, legal, and information services. Services for the over 21 year olds are practically non-existent. Those few persons identified as served were generally in facilities for the retarded.

Summary

Overall, there are few service providers and few autistic persons identified and served in the Commonwealth when the data are examined in terms of expected prevalence. Thus, not only are there gaps and insufficiencies throughout the current service system, there is evidence that the overally system is reaching only a small fraction of the expected number of persons with autism in the Commonwealth. One could safely interpret the current state of affairs as a classic example of a "vicious circle": the absence of a state definition and adequate diagnostic services has led to underidentification of persons with autism which has in turn led to underdevelopment of appropriate services for these persons.

Evaluation of Existing Services

As mentioned earlier, evaluation of existing services was conducted in facilities serving relatively large populations of persons with autism and which also advertize themselves as service providers specifically for persons with autism. Selection criteria were, thus, designed in Virginia. At the same time, a predetermined decision was made not to evaluate individual facilities but to appraise the system as a whole. Although the most detailed evaluation outcomes were elicited from site visits to cooperating facilities by evaluation teams, aspects of the Parent Survey, specifically questions related to descriptions of parent needs and satisfaction with existing services, can also be considered part of the evaluation results.

The evaluation criteria emphasizes the status, level of acceptability, and importance of each service component considered. A "priority quotient" was derived which combines three evaluation criteria into one score and which suggested areas requiring more complete implementation and/or improvement. Services were earmarked either "high priority" or "priority" for improvement if they received priority quotients scores higher than 85% or 50% of the other services, respectively.

During the site visits indirect services to clients were examined including general facility administration, client planning, and the service environment. Indirect services considered high priorities for improvement were annual plans and short term objectives. Program evaluation and aspects of the service environment were considered by facility personnel to merit priority attention.

Within the continuum of services, diagnostic services received a high priority rating. Education services were characterized by 10 high priority and 5 priority service needs. The majority of these services were, additionally, identified by parents as needs or as unsatisfactory services. The areas of high priority service need identified include education and training in total communication, sign language, group interaction, emotional expression, use of leisure time, use of the community, use of public transportation, planned experiences with non-handicapped, grooming, hygiene, specific programming to remediate maladaptive behaviors, vocational instruction and physical education. On the other hand only two services were rated as high

priority or priority by facility personnel alone, education in other communication systems, and sex education. Clearly, a high degree of agreement appears to exist in the way parents and professionals evaluate existing education services.

Evaluation of related support services revealed a relatively small number of services requiring high priority attention, namely, social work and dental services. The need for social work services was corroborated by parents. Services characterized by a priority rating included transportation, recreation, speech pathology, audiology, and nutrition. All of the services were seen by parents as needing improvement also, due to a combination of present or future needs or lack of satisfaction.

Evaluation of family services showed a high priority rating for respite services with parents again in total agreement. Family support (group meetings) and training were judged as priority services and for these services parents also reported present and future needs for training.

Employment services did not receive priority ratings, quite possibly to the very small number of such services offered by the facilities evaluated and due to the skewed age range of the respondents.

In contrast, the majority of living services received priority ratings; child day care received a high priority rating while residential services for children and adults and leisure/recreation services earned priority ratings. However, in the area of living services, parents showed little inclination to similarly judge services. Only for leisure/recreation services did parents agree with evaluators.

Summary

In sum, parents and agency personnel showed remarkable similarities in their evaluative responses to existing services in all areas except living services when the needs and level of satisfaction of parents were examined. These results lend themselves to the interpretation that the evaluation system itself may be a valid assessment procedure. Thus, indirect services that appear to require improvement include the writing of annual plans and short term objectives, components of the individualized education plan. The greatest number of high priority needs were found to be in the area of education and training, specifically for services in language, socialization, independence, use of the community, and behavior management. Respite care services for the family and child day care were also reported as requiring high priority attention.

Current Service System - Overview of Needs

By now it should be clear that the current service system is a complex organization notwithstanding the small population it serves. Attempting to describe the system via the different study instruments and procedures brings to mind the proverbial blind men who sought to describe an elephant, each touching a different part of the megalithic creature. In order to bring together the several perspectives presented so far, an overview of the service system, insofar as it relates to the needs within the continuum of direct services, is presented next.

Table 22

Current Service System - Overview

Service	Parent Survey[1]	Descriptive Survey[2]	Evaluation Form[3]	Total Responses
I. Identification				
-diagnosis		x	x	2
II. Education and Training				
A. Language				
-language training	xx			2
-speech therapy	x	x		2
-sign language	x		xx	3
-total communication	xx	x	xx	5
-other		x	xx	3
B. Socialization				
-play skills	xx			2
-peer interaction	xx			2
-interaction w/authority	xx			2
-group interaction	xx		x	3
-emotional expression	xx		x	3
-use of leisure	xxx		x	4
-use of community	xxx		xx	5
-use of transportation	xx	x	xx	5
-planned experiences w/non-handicapped	xx		xx	4
-sex education			xx	2
C. Personal Independence				
-grooming	x		xx	3
-hygiene	x		xx	3
-independent living	xx			2
D. Academics				
-physical education	xx			2
F. Specific Programming to Remediate Maladaptive Behavior	xx		x	3
G. Prevocational	xx			2
H. Vocational	xxx	x	x	5
I. Expressive Development				
-dance	x	x		2
-music	xx			2
-art	xx			2
III. Related Support				
A. Transportation	xx		x	3
B. Recreation	xxx		x	4
C. Counseling	xx			2
D. Psychotherapy	xx	xx		4

Table 22 (continued)

Service	Parent Survey[1]	Descriptive Survey[2]	Evaluation Form[3]	Total Response
F. Psychological Consultation	xx			2
I. Social Work	x		xx	3
J. Audiological	x		x	2
L. Dental			xx	2
M. Music, Dance, Art Therapy	x	x		2
O. Nutritional/dietary	x	xx	x	4
IV. Family				
B. Training	xx		x	3
C. Counseling	x	x		2
D. Respite	x	xx	xx	5
E. Support	x	x	x	3
V. Employment				
A. Sheltered	xx	x		3
B. Supervised/subsidized	x	xx		3
C. Vocational Rehabilitation	x	xx		3
VI. Living				
A. Adult Day	x	xx		3
B. Child Day		xx	xx	4
C. Leisure/recreation	xx	x	x	4
VII. Social, Legal and Informational		xx		2

[1]Parent Survey - the services received 1 to 3 x's depending on the number of the following comments by parents: "current need", "future need", and/or "not satisfied". (See also Table 3)

[2]Descriptive Survey - the services received 1 or 2 x's depending on whether the service was offered by less than 50% (x) or 25% (xx) of the facilities responding. (See also Table 15).

[3]Evaluation Form - the services received 1 or 2 x's based on wehther the service needs High Priority (xx) or Priority (x) attention. (See also Appendix H).

Table 23

Total Number of Identified Autistic Persons Receiving Services In Virginia

Age	Virginia* Population	Expected** Autistic	Identif. Autistic	Ident. Served	Specific Services	No. Served	% Served of Expected
0 - 5 Years	537,007	806	35	30 (3.7%)	Identification	25	3.1%
					Education	27	3.3
					Related	26	3.2
					Family	26	3.2
					Employment	6	0.7
					Living	9	1.1
					Social	19	2.4
6 - 12 Years	733,681	1101	150	141 (12.8%)	Identification	124	11.3
					Education	129	11.7
					Related	133	12.1
					Family	129	11.7
					Employment	21	1.9
					Living	63	5.7
					Social	99	9.0
13 - 21 Years	908,813	1363	92	86 (6.3%)	Identification	80	5.9
					Education	82	6.0
					Related	82	6.0
					Family	73	5.4
					Employment	24	1.8
					Living	43	3.2
					Social	41	3.0
Over 21 Years	3,017,499	4526	33	27 (0.6%)	Identification	23	0.5
					Education	25	0.6
					Related	24	0.5
					Family	21	0.5
					Employment	16	0.4
					Living	13	0.3
					Social	16	0.4
Total***	5,197,000	7796	316	295 (3.8%)			

*Based on estimates of the resident population July 1, 1979, U. S. Bureau of the Census.

**Based on incidence of 15 per 10,000.

***Totals do not add up in all cases because ages were not given for all identified autistic persons.

The overview of the needs on the continuum of services is presented in Table 22. Only those services which were identified more than twice by respondents on a combination of the three study instruments (Parent Survey, Descriptive Survey, or Evaluation Form) were further analyzed. Irrespective of the origin of responses, it is possible to weigh each service according to the number of responses received; thus, a service with five responses (or "x's") would indicate a significant, first rank service gap or need while a service with 2 - 3 responses (or "x's") would indicate relatively less need for development and/or improvement.

The service components which, therefore, appear to represent a first rank need (5 x's) are:

-total communication
-use of community
-use of transportation
-vocational training
-respite care

The configuration of first rank needs suggests a strong value among respondents for opportunities to provide persons with autism with skills leading to independence. Recognition seems to be given, also, to parents and their need for temporary "leaves of absence" from their autistic offspring through the service of respite care.

Inspection of second ranked services (4 x's) reveals the need for development of the following:

-use of leisure time
-planned experiences with non-handicapped
-recreation
-psychotherapy
-nutrition/dietary
-child day care
-leisure/recreation

The emphasis, once again, appears to be on those services designed to normalize as much as possible the life experiences of persons with autism by providing training in use of community and leisure activities. Note also should be made of the high priority rating given to child day care, suggesting that the majority of respondents value deinstitutionalization of persons with autism. The diverse needs of persons suffering from an, at times, severe and far ranging handicap are acknowledged in the emphasis given to psychotherapy and nutritional/dietary services.

The third ranked services (3 x's) exhibited once again a preponderance of needs in the area of education and training with an emphasis on socialization and personal independence skills:

-sign language
-play skills
-group interaction
-emotional expression
-grooming

-hygiene
-specific programming for maladaptive behaviors
-transportation
-social work
-family training
-family support
-sheltered employment
-supervised/subsidized employment
-vocational rehabilitation
-adult day care

Needs for training and support services for families were often indicated as were also employment services. The additional need for adult day care was perhaps all the more significant given the small number of adult persons with autism studied and suggests the trend for parents and professionals to seek less restrictive environment for the persons with autism.

The fourth ranked services (2 x's) were represented by a smattering of services:

-diagnosis
-language training
-speech therapy
-play skills
-peer interaction
-interaction with authority
-sex education
-independent living
-physical education
-prevocational
-dance
-music
-art
-counseling
-psychological consultation
-audiological
-dental
-music, dance, art therapy
-family counseling
-social, legal information

The services so ranked appeared to follow the trends noted earlier.

Summary

Inspection of the services most frequently responded to by parents and professionals highlighted current needs in the service system insofar as direct services are concerned. Many of the needs were related strongly to values of greater social, vocational and independence skills within the persons with autism. Services designed to assist the family with its autistic family member were also paramount. The overview just provided does not address the needs for administrative services nor does it address the question of the geographical location and density of services provided. These are also important issues, issues that must be studied further by appropriate planning groups.

Final Summary

There is a story hinted at, but untold, between the lines of the study - the human misery, frustration and failure felt by the persons we seek to understand better through our scientific methods. It is hoped that the quantity of information presented here will not obscure the truly impoverished number and kinds of services collectively being offered at this time to persons with autism. The effects of inadequate or inappropriate services on their ability to learn and grow are all the greater considering the stress already experienced by persons burdened with such a severe condition.

Nor are the human "opportunity" costs to individual autistic persons the only ones which this sad lack of identification mechanisms and services foretell. The costs to local and state government, due to failure to identify the handicapped as such and to train them for adequate or semi-independent living, are enormous and long-term. The choice which must be made, which prompted state policymakers to commission the present study, is between providing life-long, costly support services and establishing adequate training for independent, normalized life and work.

In Virginia, the handicapped, severely impaired, and vocationally disabled are the subject of many laws under which the state is declared to have a positive duty to assist these people so long as they continue to be dependent on such support. There is, therefore, no question that the taxpayer will either pay now or pay later. This study makes it clear that the interest of the taxpayer and of the state are being undermined by a failure to systematically identify and train autistic persons for a life of other than dependency upon state-provided services. The authors of this study believe that these interests must be addressed, especially as the costs of providing life-long support services are dramatically increasing, and that the recommendations in the following section can serve as a framework within which the needs of the taxpayer, or families, and of the persons themselves can be met in a systematic manner.

Although autism is, in many cases, a severe and lifelong handicap, and successful remediation effects difficult to achieve, these efforts are imperative. The very nature of autism, problematic, multidimensional, suggests its solution - a multidimensional approach through service integration and community effort. It is hoped that the great needs illustrated by the present study will provide the impetus to take the next step toward the planning and provision of greater numbers and more effective kinds of services to persons with autism in Virginia.

VI. RECOMMENDATIONS

Principles

The underlying principles upon which the recommendations are based are as follows:

1.) Autistic persons do learn when provided with opportunities for appropriate training and treatment; the service delivery system should enable persons to develop their ability and potential to the fullest possible extent, no matter how severe the degree of disability. Service planning should begin with a focus on the youngest age group of persons with autism.

2.) Persons with autism should have unimpeded access to special education and other services that are appropriate to their needs. Not having the service already in existence or having only one or two children requiring the service should not mitigate against the service being provided. The service delivery stystem should not be discriminatory either by design, structure, oversight or ignorance.

3.) Services to autistic persons in isolation are not adequate but must be extended to services for the person and the family in order to assure the structure, consistency, and coordination that will insure successful intervention.

4.) Interagency coordination is essential in order to provide a meaningful continuum of service to persons with autism.

5.) Responsibility for providing services must be clearly assigned to appropriate departments, agencies and specific programs so that respective roles can be clarified and appropriate services provided.

Approach

The recommendations originate from the analysis of the data generated by the present study and are organized along three different parameters. First, the recommendations are designed to be implemented by three different levels of government and agencies along the continuum of regulatory bodies and service providers (Virginia General Assembly, Overall Advisory Committee, state departments, regional planning organization, local planning organizations and specific programs and agencies). Second, the recommendations are classified according to the different categories of services required by autistic persons (identification; education, training and treatment; related support; family; employment; living; and social, legal, informational). Third, the recommendations are aimed at different age groups (0-5,6-12, 13-21 and over 21).

Specific Recommendations

Identification and Diagnostic Services

In the area of Identification and Diagnosis, the results show that Virginia children are underdiagnosed and that many parents are traveling more than 50 miles and out of state to obtain diagnostic services. Rectification of this problem is at the core of providing appropriate services. Recommendations regarding diagnostic services cross all ages and all government and service providers.

To assure that Identification services are available, it is recommended that:

1.) The General Assembly pass legislation adopting a state definition of autism. The study recommends acceptance of the definition adopted by the National Society for Autistic Children and the slightly modified version found in the Diagnostic and Statistical Manual III. These definitions are broad and meet the needs of medical personnel and educators.

2.) The State Department of Education encourage the colleges and universities in Virginia to provide coursework in identification of the autistic child in both the education and psychology curriculae.

3.) The State Department of Education and the localities work together to make provision for accessible diagnostic centers in each region on Virginia. It is desirable that these centers be regionalized since autism is a low incidence disability and centers that serve larger numbers of clients would have the potential for more accurate diagnosis and centralized follow-up. State universities and Child Development Centers would be logical locations to center such diagnostic services.

4.) The State Departments of Education, Health, and Mental Health and Mental Retardation establish a separate category of "autism" to collect information about needed services based on the identification of persons.

5.) The localities concentrate child find efforts toward early identification of persons with autism. A state definition and diagnostic guidelines will aid in child find and will assure that children are receiving appropriate services from the earliest age possible.

6.) The localities review evaluations of persons in existing programs to identify those with autistic and autistic-like characteristics who are currently being served in programs not designed to meet their needs.

Education, Training, and Treatment Services

In the areas of Education, Training, and Treatment there are serious deficits in Virginia's ability to serve the school aged population of

persons with autism within the few existing programs.

To assure that Virginia can provide both adequate and appropriate services it is recommended that:

1.) The Virginia Overall Advisory Committee on the Needs of the Handicapped establish a subcommittee on autism to assure compatibility and coordination of services provided across state departments. The Overall Advisory Committee is an existing structure that has interdepartmental responsibility.

2.) The General Assembly and the State Department of Education:

   a. designate and fund model programs and demonstration schools.
   b. provide funding for staff training of new teachers and teachers already serving persons with autism including:

      1.) writing appropriate individualized education plans.
      2.) safeguards to behavior management.
      3.) techniques to ensure family involvement and coordination of home/school learning.
      4.) practica in teaching persons with autism.
      5.) technical assistance to teachers in the field.

3.) The State Department of Education in coordination with the Virginia Council on Higher Education provide guidelines to higher education regarding the core curriculum for teachers approved to teach persons with autism.

4.) The Division of Special Education devise guidelines for services to autistic persons as the Division has done for other handicapping conditions, for example, with regard to curriculum, student-teacher ratios, and the use of this document.

5.) The State Department of Education and the localities work together to provide classes specifically designed for persons with autism either within the local school system or within the region. A specific supervisor in the Division of Special Education should be assigned this responsibility.

6.) The localities provide administrative support for teachers of the autistic including:

   a. preservice training.
   b. inservice training and technical assistance.
   c. monitoring of behavior management procedures used in the classroom.
   d. monitoring of home/school coordination.

7.) Local school systems and specific agencies must be made aware of the need for additional programming that is well documented in the present study. Several areas stand out as being

particularly critical:

a. individualized instruction for pre-schoolers enrolled in non-categorical pre-school handicapped programs.
b. persons assigned the responsibility of ensuring program consistency and coordination for each autistic child.
c. use of evaluative instruments for program development and needs assessment.
d. evaluation of program effectiveness.
e. programs must be established to meet the statewide deficit of services to the 13 - 21 age group of persons. The focus of these programs must be:

   1.) language development
   2.) practical life skills
   3.) social skills
   4.) group skills
   5.) vocational training

Related Support Services

In the area of Related Support Services there are critical needs for guidelines to schools regarding service to all age groups. It is recommended that:

1.) The State Department of Education establish guidelines for mandatory levels of speech and language training to be available to persons diagnosed as autistic an autistic-like.

2.) The State Department of Education develop guidelines for coordination of all resource or related support services offered to persons with autism.

3.) The specific programs assure that related support services are coordinated across school and home to provide a meaningful learning environment so that skills may be generalized across settings.

Family Services

Services to the families of persons with autism are currently a critical need in Virginia. The study found few family services available to families of autistic persons who are not in residential or institutional care. There are no residential care facilities in Virginia currently designated to serve autistic persons over 14 years of age in either a campus - or community-based setting. The study recommends that:

1.) The Overall Advisory Committee appoint a subcommittee which would serve as advocate for services to autistic persons and their families.

2.) The Departments of Mental Health and Mental Retardation, Social Services, and Education coordinate their efforts to design and/or encourage existing services to provide:

a. Training for families of persons with autism.
b. Respite care for children and adults of all ages in homes or facilities with staff trained to meet special needs.
c. Advocacy for services to meet the needs of familes.

Employment Services

The complete lack of services for the adult population with autism requires immediate attention by all agencies under this umbrella of Human Resources. The study, therefore, recommends that:

1.) A state department be designated by the Secretary of Human Resources in coordination with the Secretary of Education to provide training, counseling, and job placement to persons with autism.

2.) Funding be provided by the appropriate departments so the specific workshops or vocational rehabilitation services designated to provide these services have adequate funding to provide on-the-job supervision to the population who must be taught specific skills in order to be successfully employed.

3.) Funds be provided to insure follow-up on job placements so that persons have continued support for on-the-job problems should they arise.

Living Services

In the area of Living Services no families or agencies in Virginia reported offering living services to persons over the age of 14. To provide appropriate services Virginia must develop a continuum of living services that will lead persons to the least restrictive environment. The study recommends that:

1.) The Virginia Overall Advisory Committee designate a specific department to assume the responsibility for further planning for and development of living services which would be an alternative to institutionalization.

2.) The General Assembly and Virginia Overall Advisory Committee study the feasibility of initiating a "family subsidy" program in which families are guaranteed monthly payments to purchase needed in-home and other support services and that would enable the families to keep the person with autism at home rather than in an institution.

Social, Legal, and Informational Services

In the area of Social, Legal, and Informational Services, it is recommended that:

1.) Use be made of a computerized management information system such as found in the State Department of Health; this system

is a centralized data information system shared with the Department of Mental Health and Mental Retardation and would be appropriate for the planning, organizing, and evaluating of services as well as following up on clients receiving services.

2.) Listings of services in Virginia available for persons with autism be distributed including information on:

a. diagnostic centers
b. educational facilities
c. residential facilities
d. vocational training programs
e. living services

3.) The information generated by the present study be disseminated to professionals on request.

4.) The Virginia Society for Autistic Children be enabled to provide information and referrals regarding services in the Commonwealth.

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May 25, 1979

REQUEST FOR PROPOSAL

The Developmental Disabilities Unit of the Department of Mental Health and Mental Retardation is soliciting responses to a Request for Proposal to conduct a study of services provided to persons with autism in the Commonwealth of Virginia. The study will be expected to address the following areas:

1. A comprehensive review of literature on autism, including its nature, cause, and treatment. A bibliography must be included.

2. A recommended operational definition of autism for service providing agencies in the Commonwealth.

3. Enumeration of the numbers and demographic characteristics of persons in both public and private programs in the Commonwealth who have been diagnosed as having autism.

4. A description of the services, and cost of services, currently being provided to persons diagnosed as having autism in the Commonwealth.

5. Evaluation of the quality and appropriateness of services offered to persons with autism in the Commonwealth. Identification of existing gaps in service programs for autistic persons in the Commonwealth.

6. Recommendations for a desired service spectrum with a model(s) of a service organization for the delivery of services to persons with autism, including, but not necessarily limited to, recommended individual service plans.

ELIGIBILITY REQUIREMENTS FOR INTERESTED POTENTIAL RESPONDENTS

1. State or local public agencies within the Commonwealth of Virginia.

2. Private, non-profit organizations within the Commonwealth of Virginia.

APPENDIX B

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APPENDIX C

ANNOTATED BIBLIOGRAPHY ON AUTISM

ANNOTATED BIBLIOGRAPHY ON AUTISM

From

A STUDY OF STATEWIDE SERVICES FOR PERSONS
WITH AUTISM IN VIRGINIA

Conducted by

GRAFTON SCHOOL

SCHOOL FOR CONTEMPORARY EDUCATION

Developmental Disabilities Unit Grant #79-16

ANNOTATED BIBLIOGRAPHY ON AUTISM[1]

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[1]Lori DeZarn is the first author.

ACKNOWLEDGEMENTS

The members of the research staff would like to thank the following people for the help and assistance they gave so willingly, for without them the Annotated Bibliography could not have been accomplished:

Robert DeVillis
David Krug, Ph.D
Brenda Lancaster
Gary W. LaVigna, Ph.D
Lee Marcus, Ph.D
Don Oswald
Ruth Page
David Park
Michael Rutter, M.D.
Eric Schopler, Ph.D
Frank Warren
Members of the Advisory Committee
The Staff at the DeJarnette Center for Human Development

The annotated bibliography represents a partial product of a larger study entitled "A Study of Statewide Services for Persons with Autism in Virginia", Developmental Disabilities Unit Grant #79-16 by

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Copies of both the original study and an abridged version are available and may be obtained by contacting:

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HISTORY OF AUTISM

Most likely there have always been persons with autism, although they were never identified as autistic, for they were probably considered feebleminded, retarded, or mentally ill. Several singular accounts can be found throughout history. Recorded historical accounts of autistic persons date back to 1799, when Victor, an eleven year old boy, was found in the woods of France. In 1920, Witmer, an American psychologist, published his techniques for teaching a small boy of 2, who today would be described as autistic. It was not until 1943, when a child psychiatrist identified a group of children as having several common characteristics that the syndrome was identified as "early infantile autism". Leo Kanner described eleven children as having "a number of essential and unique characteristics most of which are still regarded as the primary characteristics of autism." Kanner's identification of the syndrome "autism" led to some confusion with Bleuler's use of the word with regard to the schizophrenic's "active withdrawal from contact with reality in order to live in an inner world of fantasy". Although much more has been learned about autism since its discovery in the 1940's, Kanner's contribution to defining the syndrome was invaluable, as was his followup work on the original eleven children, since it was the first written about the autistic adult. His etiological theories gave rise to a number of questions, most of which are still unanswered today. One theory, which he later discounted, was perpetuated by Bruno Bettleheim. That theory suggested that autism was caused by "feral" mothers, who emotionally deprive their children. Though his theory was the cause of much suffering and guilt by parents of autistic children, it was never taken seriously by most researchers. Instead, the emphasis of the last two decades has been on gaining a greater understanding of the nature of autism and on developing effective methods for teaching these children.

SUGGESTED READING:

Bettelheim, B. The empty fortress: Infantile Autism and the Birth of the Self. New York: The Free Press, 1967. This text presents the author's observational and treatment-oriented research with several autistic children. Three case studies are described extensively, also the treatment these children received. Bettelheim attempts throughout the book to argue his theory of the cause of autism - that being emotional deprivation by parents, especially the mother. Freudian overtones prevail throughout the text. An interesting discussion of the literature on autism concludes the book, which is probably most valuable to those interested in an early historical overview of the research.

Itard, J. M. G. The wild boy of Aveyron. New York: Appleton-Century-Crofts, 1962. A physician's dramatic account of his experience with Victor, a boy found wandering naked in the woods of France. The boy, believed to be handicapped due to his isolation from humans, showed many of the features of autism. This touching book tells the interesting story of Itard's attempts to educate Victor.

Kanner, L. Childhood psychosis: Initial studies and new insights. Washington, D.C.: V. H. Winston & Sons, 1973. This text presents a collection of Leo Kanner's articles from the 1950's, 60's, and 70's. Included are his case descriptions of the original eleven autistic children he discovered in 1943, and his followup study of those individuals twenty-eight years later. This collection is interesting from a historical perspective because it illustrates the shifts in professional thinking through approximately thirty years. It is also interesting in a biographical sense as it highlights Kanner's contributions to the field of child psychiatry.

Schopler, E. Treatment of autistic children - historical perspective. In P. Mittler (Ed.), Research to practice in mental retardation. Proceedings of the Fourth Congress of the International Association for the Scientific Study of Mental Deficiency (Washington, D. C.) (Vol. 1). Baltimore: University Park Press, 1977. This chapter reviews what is known or inferred about autistic children and their treatment historically. It also reviews how they were understood and treated during the several decades following Kanner's (1943) initial discovery of the syndrome. Finally, the most current approaches to autistic children are summarized.

ADDITIONAL SUGGESTED READING:

Eberhardy, F. The view from the couch. Journal of Child Psychology and Psychiatry. 1967, 8, 257-263

Gesell, A. Wolf child and human child. New York: Harper, 1941

Kanner, L. Autistic disturbances of affective contact. Nervous Child. 1942, 2, 217-250

DEFINITION OF AUTISM

Kanner was the first to define characteristics of the syndrome he identified in 1943. He noted several behavioral characteristics which he felt were common to all children yet different from features of children with other psychiatric disorders. These were:

-an inability to develop relationships with people
-a delay in speech acquisition
-non-communicative use of speech after it develops
-delayed echolalia
-pronominal reversal
-repetitive and stereotyped play activity
-an obsessive insistence on maintenance of sameness
-a lack of imagination
-a good rote memory
-a normal physical appearance
-abnormalities evident in infancy

Kanner defined these children as having "autistic disturbances of affective contact". Kanner and Eisenberg in a later study observed that autism could develop after a year or two of normal development. Kanner's suggestion that autism was a "syndrome" (a condition defined by clusters of symptoms) led to more recent research to distinguish between specific and universal characteristics, that is, which symptoms could occur in those labeled autistic, but might also occur in other abnormalities, and which symptoms are specific to the syndrome of autism. Rutter's attempts to identify specific characteristics revealed the following three broad groups:

1.) a profound and general failure to develop social relationships with regard to intellectual level.
2.) language retardation, and deviant language development with impaired comprehension, echolalia and pronominal reversal, and
3.) ritualistic or compulsive phenomena; "insistence on sameness".

In addition to the criteria of onset before 30 months of age, Rutter recommends that the above criteria be applied to determine a child's inclusion in research samples.

A similar definition, written by Ritvo & Freeman in 1977, was accepted for use by the National Society for Autistic Children (NSAC). Their definition specifies the following as essential characteristics:

1.) manifested before 30 months of age
2.) disturbed developmental rates and sequences
3.) disturbed responses to sensory stimuli
4.) disturbed speech, language and cognitive capabilities
5.) disturbed capabilities to relate to people, events and objects.

The NSAC definition also includes sections that identify associated clinical features, provide information on the intelligence of autisitic children and describe the incapacitating nature of the syndrome. Remaining sections included in the NSAC definition discuss: age of onset, etiology, incidence and sex ratio, complications, differential diagnosis, predisposing factors, family factors, and operational criteria. An important final note is that the NSAC definition requires that the five essential characteristics mentioned earlier are required in order to make a definitive diagnosis of autism.

The similarities between the Rutter and NSAC definitions pertain to onset before 30 months, disturbed language development and disturbed ability to relate to others. The differences in the two definitions pertain to NSAC's inclusion of sensory disturbances, which Rutter considers to be more specific to some persons, and NSAC's inclusion of disturbed developmental rates which Rutter does not include. These differences can be explained by taking into consideration each author's emphasis and the need each definition meets. Thus, both are "working" definitions, but while Rutter's criteria are more applicable to research needs, Ritvo and Freeman's definition responds to the needs of the National Society, a parent group whose objective is to promote social and political action on behalf of autistic persons.

A note about the most recent trends which relate to the educational needs of these children is warranted. Wing (1979) emphasizes that when considering the educational needs of those with autism, we must again look at a broader definition to include all those children who require a unique, individualized educational structure. These persons have the following "autistic-like" features (Warren & Benson, 1980):

1.) Severe problems in taking part in two-way social interactions - A minority will make social approaches, but these will be one-sided and odd. They may talk of things that interest them, but will not respond to other people's attempts to change the course of conversation. Most will not make social approaches at all. Some will passively accept approaches, while most are aloof and indifferent; though they might like tickling and a brief cuddle.

2.) Problems with language and communication - All have difficulty understanding and using nonverbal as well as verbal language. They do not use facial expression, gestures, vocal intonation, making and breaking eye contact to convey meaning. Many sociable mentally retarded children have no spoken language, but they use the non-verbal means of communication that are appropriate for their mental ages, and this is one of the ways in which they differ from children with autism and related communication handicaps.

3.) Severe impairment in the development of imaginative activities - Most have not pretend play or other imaginative activities. A small majority may have a very limited range of such pursuits. Such pretend play is characterized by narrowness of theme, repetitiveness, and a concrete pedantic nature. Often such play consists simply of copying the actions of other children, of well known adults, or a favorite television character. The play tends to remain the same for years, and not be modified by suggestions from other people. In the absence of creative, flexible pretend play (which fills so much of the time of normal children) the autistic or autistic-like child passes the time with repetitive, stereotyped activities of all kinds, varying from simple to complex, but all equally lacking in aim of meaning.

In summary, it appears that although there seem to be a few universal characteristics of persons with autism, it is important to determine th focus of the need for the definition. Thus, it is important to understand the definitional criteria in use when reviewing research studies of the literature in the field of autism.

SUGGESTED READING:

Kanner, L. Autistic disturbances of affective contact. Nervous Child, 1943, 2, 217-250. In this article, Kanner describes the original eleven children he observed to have a set of characteristics that set them apart from other handicapped (psychotic) children. The primary features he noted were a profound lack of relating to others and the desire for sameness shown by these children. These children were followed up in a later study.

Ritvo, E. R., & Freeman, B. J. NSAC definition of the syndrome of autism. Journal of Autism & Childhood Schizophrenia, 1978 8 (2), 162-167. This working definition of autism was approved by the Board of Directors and Professional Advisory Board of the National Society for Autistic Children in July of 1977. It lists the following characteristics as critical for a diagnosis of autism; 1.) signs and symptoms present prior to 30 months of age, 2.) disturbances of developmental rates and/or sequences, 3.) disturbances of speech, language & cognitive capacities, 4.) disturbances of responses to sensory stimuli, 5.) disturbance of relating to people, events & objects.

Rutter, M. Diagnosis and definition of childhood autism. Journal of Autism & Childhood Schizophrenia, 1978, 8 (2), 139-161. This interesing article reviews the research that has led to the presently accepted characteristics of autism. Although there is still argument concerning the essential characteristics, five have been recognized as most crucial. The validity of the syndrome is discussed by comparing autism to various other childhood disorders. Finally, the NSAC and Rutter definitions are discussed in terms of their similarities and differences.

Schopler, E. On confusion in the diagnosis of autism. Journal of Autism & Childhood Schizophrenia, 1978 8 (2), 162-167. Definitions and diagnoses of childhood autism by M. Rutter and by the National Society for Autistic Children are presented. They are one example of the difficulties in reaching consensus on a definition of autism. It is important that researchers be aware of these difficulties and explicitly identify specific characteristics and selection purposes implemented.

Wing, L. Diagnosis, clinical description and prognosis. In Early Childhood Autism. Oxford, England: Pergamon Press, 1976. This chapter reviews the literature on diagnosis and definition, discusses the primary characteristics in detail and considers the issue of differential diagnosis. Prognosis and changes with age are discussed also.

OTHER SUGGESTED READING:

Akerly, M. S. The politics of definitions: How autism got included in the developmental disabilities act. Journal of Autism and Developmental Disorders, 1979, 9 (2), 221-231.

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PREVALENCE

Due to the comparative rareness of the syndrome of autism and its history of being difficult to identify and define, sound epidemiological studies with large samples were not conducted until recent years. Since the mid-1960's, researchers have attempted to estimate the prevalency of autism in several major studies. Studies conducted in Wisconsin, Denmark and England have generated prevalency figures ranging from 2 to 5 per 10,000, a range of figures that probably results from varied samples, different study locations, and differing criteria for inclusion. A generally accepted figure for estimating the number of "classic" autistic persons is 3-4 per 10,000. However, in 1979, Wing presented a case for considering not only the "classic" or Kanner syndrome child, but all children with autistic-like characteristics who will require a specialized, individualized educational structure. She estimates that there are 10 to 20 such children in a population of 10,000. As more is learned about the educational needs of these children, it is probable that this new approach to estimating the prevalence of autism will be adopted.

SUGGESTED READING:

Lotter, V. Epidemiology of autistic conditions in young children. Social Psychiatry, I, 1966, 124-134. Lotter investigated all 78,000 children aged 8, 9 and 10 in the former county of Middlesex, England. Following preliminary screening, 135 children were intensively tested and observed, and their parents and teachers interviewed. The children were rated and placed in three groups on the basis of these scores. Results yielded a prevalence rate of 2 per 10,000 in the nuclear autistic group, and a sex ratio of 2.75 males to one female.

Treffert, D. A. Epidemiology of infantile autism. Archives of General Psychiatry, XXII, 1970, 431-38. The author studied severely disturbed children ages 3 through 12 in the state of Wisconsin, and discovered 3.1 cases of childhood schizophrenia per 10,000 children. Of these children, 25% or .7 per 10,000 were diagnosed autistic. He reports a sex ratio of 3.4 boys to one girl, and significantly higher education levels in parents of those diagnosed autistic.

Wing, L. Social, behavioral and cognitive characteristics: an epidemiological approach. In Autism: A reappraisal of concepts and treatment. Rutter, M. & Schopler, E. (Eds.). 1978, 23-42. In this paper, the author describes an epidemiological study conducted out in an area of London in 1971. After screening 35,000 infants and children aged 0-14, 1,000 were assessed and observed intensively. Wing reports a prevalence rate of 4.8 per 10,000 of "Kanner syndrome" children. Further discussion ensues concerning the cognitive, social and behavioral characteristics of the children studied.

Wing, L. & Gould, J. Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. Journal of Autism and Developmental Disorders, 1979, 9, 11-29. In this paper, Wing discusses the complications involved in diagnosing autism. She describes her research study on prevalency which involved screening 35,000 children aged 0-14 in an area of London. The results indicated a prevalency rate of 4.9 per 10,000. Further, she discusses the need and her rationalization for expanding this estimated rate to 10-20 per 10,000 to include those children requiring similar specialized, individualized educational planning.

ADDITIONAL SUGGESTED READING:

Lotter, V. Social adjustment and placement of autistic children in Middlesex: A follow-up study. Journal of Autism and Childhood Schizophrenia, 1974, 4(1), 11-32.

Wing, L. Epidemiology and theories of etiology. In Early childhood autism, Wing, L. (Ed.), 1976, 65-92.

Much has been written about the widespread confusion involved in diagnosing autism and the ramifications of an inaccurate diagnosis. The literature is filled with articles dealing with researchers' attempts to pin-point those few characteristics that are specific and essential to an accurate diagnosis of autism. Many have endeavored to create checklists, scales and other types of diagnostic systems in order to diagnose the syndrome and many more studies have compared the resultant diagnostic systems. Yet, for the most part, the results of these studies are inconclusive and lend support to the belief that autism is a highly variable syndrome, and affects no one individual in the same way. This realization increases the difficulty in educating those who must be involved in the multidisciplinary approach to the diagnosis of autism.

Schopler acknowledges the diagnostic confusion arising from the complexity of the concept of autism, and discusses two other sources of the confusion. One source has to do with the perspective of the person doing the defining. A researcher may be looking for a very clear delineation of the symptoms, whereas a legislator considering the educational needs of a group of children, may use a much "looser" definition. A second source of confusion, according to Schopler, derives from a lack of knowledge or "scholarly rigor" which can be reduced through experience with autistic children, observation and knowledge of the literature.

Lorna Wing noted recently that in many parts of the country it is still very difficult to find someone who knows about autism. She agrees with Schopler's comment that much knowledge about the syndrome can only be acquired through years of experience, for diagnosis is made difficult by the "enormous variation in the clinical picture".

Wing mentions five factors related to the clinical picture which complicate the problem of diagnosis. First are the enormous variations in severity that occur. The autism can be very mild or severely incapacitating. Second is the fact that autism is almost always accompanied by additional handicaps. Autistic individuals may be deaf, blind, have problems with motor function, or may have or possibly develop seizure activity. Rutter reports that 70% to 80% of autistic children are also mentally retarded. Third, age is an important variable with regard to the behavior of an autistic person, regardless of severity. The characteristics of persons with autism change as they grow older, and Wing argues that this should not be a basis for disputing a diagnosis of autism. For example, older autistic persons tend to seek the affection of others more often and many become more social; mildly autistic adolescents may have severe problems with socializing which may in turn affect their behavior. Fourth, the child's sex makes a difference. Although the accepted sex ratio for autism is four males for each female, females are believed to be more severely handicapped. Wing also speculates that girls who have autism may be more socially aware than boys. Fifth, the environment has an effect on the behavior of those with autism just as it

does with normal individuals. Behavior may vary greatly as will learning rates depending on the environment.

Add to these five complicating factors the variability in IQ scores of autistic persons and the inherent differences among all people and it becomes apparent why understanding autism is an arduous task. The complexities of the syndrome deem it imperative that diagnosis deal with several different facets of a child's problems. The following questions are necessary: Behaviorally, does the child have autism? Intellectually, to what degree is the child mentally retarded? Medically, is there any underlying diagnosable disease? Psychosocially, what are the strengths and limitations of the child's environments? Consideration of these basic questions will not only aid in accurately assessing and diagnosing a child's problem but also help indicate his essential needs for treatment.

SUGGESTED READING:

Lichstein, K. L. & Wahler, R. G. The ecological assessment of an autistic child. Journal of Abnormal Child Psychology, 4(1), 1976, 31-54. One child diagnosed autistic was observed in his natural environment at school and at home. This "ecological assessment" resulted in the following findings: the child exhibited a variety of responses in a variety of settings, an absence of relatedness to others but more response to adults, which was reflected by a reduction in self-stimulation with increased adult attention, and evidence of an elevation of some undesirable behaviors accompanying the suppression of others.

Schopler, E., & Rutter, M. Subgroups vary with selection purpose. In M. Rutter & E. Schopler (Eds.), Autism: A reappraisal of concepts and treatment. New York: Plenum, 1978, 507-517. The problem of classification and the possible use of a multiaxial system of classification are discussed in this concluding chapter. Many specific mechanisms underlie the disorder. Research may prove more valid and effective when samples are selected for appropriate characteristics and when the selection purpose is clearly specified.

Rutter, M. Childhood schizophrenia reconsidered. Journal of Autism and Childhood Schizophrenia, 1972, 2(4), 315-337. The author discusses the current knowledge concerning various childhood psychoses and the characteristics that differentiate autism from these. He suggests that the term "childhood schizophrenia" has outlived its usefulness since more is known about the various childhood disorders that at one time were called "childhood schizophrenia". He also explores the implications of labeling a child with various diagnostic terms.

Wing, L. Social, behavioral & cognitive characteristics: An epidemiological approach. In M. Rutter & E. Schopler, (Eds.) Autism: A reappraisal of concepts and treatment. New York: Plenum Press, 1978. This chapter describes a study by the author that attempted to examine the characteristics of a group of autistic children found in a suburb

of London. The social, behavioral and intellectual characteristics of the children were examined extensively. Research results from prior studies were compared with the present findings. The findings of this interesting analysis have direct implications for etiological and other research for the future.

Wing, L. Tape Transcript. From the 1979 Annual Meeting of the National Society for Autistic Children, San Jose, California, 1-30. In the first part of this interesting talk, Wing discusses the considerations involved in diagnosing autism. In the second half, she describes her research study on prevalency which involved screening of 35,000 children aged 0-14 in an area of London. Results indicated a prevalency rate of 4.9 per 10,000. Further, she discusses the need and her rationalization for expanding this estimated rate to 10-20 per 10,000 to include those children requiring similar individualized educational planning.

OTHER SUGGESTED READING:

DeMyer, M. K., Churchill, D. W., Pontius, W., & Gilkey, K. M. A comparison of five diagnostic systems for childhood schizophrenia and infantile autism. Journal of Autism and Childhood Schizophrenia, 1971, 1(2), 175-189.

Ritvo, E. R., Cantwell, D., Johnson, E., Clements, M., Benbrook, F., Slagle, S., Kelly, P., & Ritz, M. Social class factors in autism. Journal of Autism and Childhood Schizophrenia, 1971, 1(3), 297-310.

Schopler, E. Changes of direction with psychotic children. Child Personality and Psychopathology: Current Topics, Vol. 1 (A. Davids, Ed.) New York: Wiley, 1974, 205-236.

Wing, L., Wing, J. K. Multiple impairments in early childhood autism. Journal of Autism and Childhood Schizophrenia, 1971, 1(3), 256-266.

ASSESSMENT

The extreme difficulty involved in diagnosing, evaluating, and developing treatment programs for autistic children has led educators and researchers to determine the importance of an accurate and comprehensive assessment of skills prior to any attempts at writing individualized treatment plans. Autistic children have, for many years, been considered difficult to assess and test because their unique characteristics, language problems and scattered skills make many tests inappropriate and the results unreliable and invalid. For years, autistic children were considered for the most part untestable, although subsequent research has disproven this idea. Studies by DeMyer, Lockyer and Rutter indicate that not only are autistic children testable, but that with careful, flexible testing, the results are reliable and have a high prognostic value. In order to discover why the testing of children with autism is so difficult, Schuler and Bohmann, Hermelin and O'Connor; Frith, and Wing chose to examine how autistic children process information. The study results led researchers to support the notion of a central conceptual deficiency in processing incoming and outgoing information.

It is generally agreed that an accurate, comprehensive assessment should be conducted by a multi-disciplinary team. At minimum, the team should include a licensed psychologist, a certified speech specialist, an educational diagnostician, parents (who assist by giving the child's history), and a doctor to perform a medical assessment. Mary Coleman, of the Children's Brain Research Clinic, states that the medical assessment should include the following: a family history and physical, an electroencephalogram, a bone-age X ray and CAT scan of the brain, and various biochemical studies. Another medical researcher questions the necessity of having some of these highly technical or expensive procedures mentioned by Coleman performed routinely, and adds hearing and vision tests as essential aspects of a medical assessment. Assessment techniques utilized should include observation, parent interview and informal assessment testing procedures. Assessment is much more than simply applying a set of tests. It involves a thorough interrogation of a child's general level of mental development, his cognitive strengths and weaknesses, his language comprehension and functional usage, his unique behavioral patterns and the motivation for these patterns.

Marcus (1979) states that many of the problems in assessment come from the frustrations of the examiner. He suggests that by using a positive, flexible approach, and reminding oneself that behavior is the autistic child's coping mechanism, the problems involved in the assessment procedure can be reduced. It appears then, the approach to the successful assessment of an autistic child needs to be like that of the education and treatment of these children - individualized and flexible.

The following list of assessment instruments are those most frequently used successfully with persons with autism. Under each test title, there is listed basic data about the instrument. The narrative following provides

further general information on the uses, strengths and weaknesses of the instrument. The narrative refers to each test's specific use with persons who have autism and may contain statements that are opinions of the study staff or advisory board reviewers. The instruments are listed alphabetically in the following categories: Developmental/ Screening Instruments, Tests of Intellectual Development, Tests of Language Development and Tests of Behavior and Social Functioning.

Assessment Instruments

Developmental Scales/Screening Instruments

Autism Screening Instrument for Educational Planning (ASIEP)

by Krug, D. A., Arick, J. R. & Almond, P.

Criterion and norm referenced
Administered individually
Age: 3 - adolescence

The ASIEP was developed to provide an objective and simple instrument for identifying and developing treatment plans for autistic students. There are five components:

The Autism Behavior Checklist:	requires no response, 10-15 minutes to administer
Sample of Vocal Behavior:	observes spontaneous vocal behavior, 10-15 minutes to administer
Interaction Assessment:	observes spontaneous social behavior, 12 minutes to administer
Educational Assessment:	requires vocal or manual gestures, and motor responses, 15 minutes to administer
Prognosis of Learning Rate:	requires manipulation of objects, 1 to 5 15 minute sessions to administer

The instrument may be valuable as a public school screening procedure designed to facilitate educational placement and as a pre- and post-measure when working with nonadaptive behaviors. Reliability, validity and standardization information are available.

ASIEP
ASIEP Educational Company
3216 N. E. 27th Avenue
Portland, OR 97212

Bayley Scales of Infant Development

by Bayley, Nancy

Norm referenced
Verbal and non-verbal response mode
Administered individually
Age: 2 - 30 months
Administration Time: 45 minutes

This instrument assesses the developmental functioning of infants,

measuring auditory perception, behavior, motor development and social development. It has three scales:

Mental Scale - yields age level or equivalent
Motor Scale - yields age level or equivalent
Infant Behavior Record - yields observational information concerning testing behaviors

These scales are especially useful for young children, and low functioning older children. Test purchase is restricted and training is necessary for administration of test. Standardization, reliability and validity data are available.

Psychological Corporation
757 Third Avenue
New York, NY 10017

Bayley Scales of Infant Development - Modifications for Youngsters with Handicapped Conditions
by Hoffman, H.

Criterion referenced
Verbal and non-verbal response mode
Administered individually
Age: 2 - 30 months
Administration Time: 45 minutes

This adaptation of the Bayley Scale assesses the cognitive development of handicapped babies by obtaining an initial score with the standard Bayley and deriving a second score by modifying the testing procedures to circumvent the effects of the infant's physical limitations. The scale is designed for those with physical handicaps.

TMA Outreach Program
Suffolk Rehabilitation Center
159 Indian Head Road
Commack, NY 11725

Boehm Test of Basic Concepts
by Boehm, Ann E.

Criterion and norm referenced
No verbal response required
Administered orally to small groups or individually
Age: K - 2nd grade
Administration Time: approximately 30 minutes

The Boehm measures student's mastery of 50 concepts that are considered necessary for success in the beginning school years. Test administration presents pictorial multiple choice items dealing with the

following concepts: quantity, number, space and time. Two forms are available in Spanish and English. Norms of the percent passing each item by grade and socioeconomic level are provided along with percentiles in the test packet. It is recommended as an effective secondary assessment for kindergarten and first grade skills.

Psychological Corporation
757 Third Avenue
New York, NY 10017

Brigance Diagnostic Inventory of Early Development
by Brigance, A. H.

Criterion referenced
Verbal and non-verbal response required
Administered individually
Age: 0 - 7
Administration Time: unknown

This instrument assesses the developmental areas of psychomotor, general knowledge and comprehension, speech and language, self-help and early academic skills. The skills are divided into over 200 functional levels arranged in sequential order. Ten developmental record books are included to show progress over time.

Curriculum Associates
6 Henshaw Street
Woburn, MA 01801

Carolina Development Profile
by Lillie, D. L. & Harbin, G. L.

Criterion referenced
No response required
Administered individually
Age: 2 - 5 years
Administration Time: Untimed

This instrument is a checklist of skills in fine motor, gross motor, perceptual reasoning, receptive language and expressive language areas. The test kit includes, for each task, a task description, developmental age, required materials and criteria for passing. It is intended for use with mildly handicapped children.

Kaplan Press
600 Jonestown Road
Winston-Salem, NC 27103

Childhood Autism Rating Scale (CARS)
by Reichler, J. and Schopler, E.

Criterion and norm referenced

Non-verbal response mode
Administered individually
Age: Pre-school age range
Administration Time: unknown

The CARS is a 15-scale rating system designed for autistic children which incorporates Kanner's primary features, additional characteristics noted by Creak, and other scales that assess symptoms characteristic of the younger child. The purpose of the scale is to rate behavior without recourse to casual explanations. The scoring for each item on this behavior observation scale occurs on a continuum from normal to severely abnormal (1 - 4) which, when totaled, places the child in one of three categories: Not autistic, Mild - Moderate Autistic or Severely Autistic. Reliability and Validity data are available.

Dr. Eric Schopler, Director
Division TEACCH
214 Medical School Wing B 207H
School of Medicine
University of North Carolina at Chapel Hill
Chapel Hill, NC

Denver Developmental Screening Test (DDST)
by Norris, G. & Nank, G.

Norm referenced
Non-verbal response mode
Administered individually
Age: 6 weeks - 6 years
Administration time: 10 - 20 minutes

This test is designed to detect children with significant social, motor or language delays. It is often used by nurses or pediatricians. A training kit is available and recommended for non-professionals.

Lodoca Project and Publishing Foundation, Inc.
East 51st Avenue & Lincoln Street
Denver, CO 80216

Learning Accomplishment Profile (LAP)
by Griffin, P. M. & Sanford, A. R.

Criterion and norm referenced
Verbal/Non-verbal response mode
Administered individually
Age: 0 - 6
Administration Time: 45 - 120 minutes

The LAP is designed to evaluate physical and mental development in the areas of fine and gross motor development, self-help, cognitive and language skill areas. The tasks for each skill are arranged hierarchically

with developmental ages provided. Reliability and validity data is available.

Kaplan Press
600 Jonestown Road
Winston-Salem, NC 27013

Learning Accomplishment Profile - Diagnostic (LAP-D)
by Griffin, P. M. & Sanford, A. R.

The LAP-D for children aged 1 - 6, is designed to assess five developmental areas: fine motor, gross motor, language, self-help and cognitive. Subskill areas in order of least to most difficult are provided for each skill area. The LAP-D was developed for the mildly handicapped and is comparable to the Psychoeducational Profile but without the emphasis on pathology. Reliability and validity data are available.

Kaplan Press
600 Jonestown Road
Winston-Salem, NC 27013

Learning Accomplishment Profile for Infants (LAP-I)
by Glover, N. E. & Preminger, J.

This instrument is designed similarly to the LAP but is comprised of items for infants and children between the ages of 0 and 13. Skill levels are assessed in the following areas: language, fine and gross motor, cognitive and social-emotional skills. Identification of the next appropriate skill is provided as well as how to teach that skill.

Kaplan Press
600 Jonestown Road
Winston-Salem, NC 27013

Preschool Attainment Record (PAR)
By Doll, Edgar A.

Norm referenced
Interview format
Administered individually
Age: 6 months - 7 years
Administration Time: 20 - 30 minutes

This instrument is designed to provide an assessment of the social, physical and intellectual functions of children difficult to examine directly because of sensory impairments, resistance to examination or cultural problems. The format includes observation and an informant interview and yields age scores and an attainment quotient which may aid in educational planning and management. Subtests include: ambulation, manipulation, rapport, communication, responsibility, information, ideation, and creativity. The Record is similar to the Vineland Social Maturity

Scale but provides a more extensive inventory of specific attainments due to its more limited age range.

American Guidance Service, Inc.
Publisher's Building
Circle Pines, NH 35014

Psychoeducational Profile (PEP)
by Schopler, E., Reichler, R. J. & Lansing, M.

Norm referenced
Verbal and non-verbal response modes
Administered individually
Age: 2 - 6 years
Administration Time: 60 - 90 minutes

The PEP is a diagnostic tool useful for planning individualized teaching programs for autistic persons. The instrument assesses six areas of mental functioning for the pre-adolescent child and also includes a pathology scale. It provides a "learning profile" for the child that can be translated into a teaching program. It is a comprehensive instrument that provides the flexibility necessary when working with autistic children. A similar assessment tool for adolescents is presently being prepared.

University Park Press
233 East Redwood Street
Baltimore, MD 21202

Rimland E-2
by Rimland, Bernard

Norm referenced
No response required
Administered individually (completed by parent)
Age: Questions pertain to ages 0 - 6
Administration Time: 20 - 40 minutes

This checklist is designed for completion by parents of children with severe behavior disorders. The checklist is scored by the Institute of Child Behavior Research, where it is stored for research purposes and parents receive a diagnosis from the Institute. A supplement to this checklist, Form E-3, is the result of further research. The E-2 is intended, for research purposes, to differentiate cases of Kanner's early infantile autism from the wider range of children called "autistic" or "autistic-like" by more recent descriptions which include more characteristics. It is not designed to determine whether or not a child is autistic for the purposes of educational placement.

Institute for Child Behavior Research
4758 Edgeware Road
San Diego, CA 92116

Vulpe Assessment Battery: Developmental Assessment/Performance Analysed Individual Programming for the Atypical Child
by Vulpe, Shirley G.

Criterion referenced
Non-verbal response mode
Administered individually
Age: 0 - 6 years
Administration Time: unknown

The Vulpe is designed to give a systematic overview of the child, evaluating basic senses and functions covering sensory intactness, muscle coordination and strength, balance and tone. It is especially helpful with the physically handicapped child. Comparable to the Psychoeducational Profile, it is useful for autistic children functioning at lower levels.

National Institute of Mental Retardation
Kensmen NIMP Building
4700 Keele Street
Downsview, Ontario, M3J, IP3

Tests of Intellectual Development

Columbia Mental Maturity Scale
by Burgermeister, Bessie B.

Norm referenced
Non-verbal response mode
Administered verbally
Age: 3 - 10 years
Administration Time: 15 - 30 minutes

This instrument, originally developed for cerebral-palsied children, consists of drawings on cards from which the subject selects the one drawing that does not belong. It yields a mental age and an intelligence quotient. Since only one type of response is measured, its usefulness may be limited for some children.

Western Psychological Services
12031 Wilshire Blvd.
Los Angeles, CA 90025

Hiskey-Nebraska Test of Learning Aptitude
by Hiskey, Marshall S.

Norm referenced
Non-verbal response mode
Administered individually
Age: 3 - 17 years
Administration Time: 45 - 60 minutes

Developed originally for the deaf, this instrument is useful with children having communication problems. The skills tested are: memory for

colored objects, bead stringing, block building, paper folding, visual attention span, puzzle blocks and pictorial analogies. Although this test is sometimes considered difficult to administer since it requires the administrator to pantomime instructions, it yields useful information from children in the moderate to high IQ range. Test purchase is restricted.

Marshall S. Hiskey
5640 Balwin
Lincoln, NE 68508

Leiter International Performance Scale
by Leiter, Russell G.

Norm referenced
Non-verbal response mode
Administered individually
Age: 2 - 18 years
Administration Time: 20 minutes - 1 hour

The Leiter consists of a response frame and response blocks with corresponding stimulus cards. The subject is directed (by pantomime) to place the correct response block on the frame when presented with a stimulus. Subtests increase in difficulty. The ease of administration makes this test a good alternative to the Hiskey-Nebraska. Leiter IQ scores have been observed by some to drop over time, indicating that scores for young children may be inflated.

Stevelting Company
1350 S. Lostner Avenue
Chicago, IL 60624

McCarthy Scales of Children Abilities
by

Norm referenced
Verbal response mode
Administered individually
Age: 2.5 - 8.5 years
Administration Time: 45 minutes - 1 hour

The McCarthy was developed to measure general intellectual abilities, strengths and weaknesses. These six scores are obtained: verbal, performance - perceptual, quantitative, composite, memory and motor. Although scoring is a bit difficult, this test is a good alternative to the WISC-R since the verbal extends to 2.5 years.

Psychological Corporation
757 Third Avenue
New York, NY 10117

Merrill-Palmer Scale of Mental Abilities
by Stutsman, Rachael

Norm referenced
Verbal and non-verbal response mode
Administered individually
Age: 18 - 71 months
Administration Time: 15 - 30 minutes

This is a performance battery of intelligence tests for pre-school through primary grades. It has 19 subtests of non-verbal abilities and is useful with the younger autistic child although it has a disadvantage in that scoring depends on speed and accuracy. This test is useful for most children since the non-verbal subtests do not require language concepts, and children enjoy taking it, though the range of concepts that are tapped is somewhat limited.

Western Psychological Services
12031 Wilshire Blvd.
Los Angeles, CA 90025

Wechsler Preschool and Primary Scale of Intelligence (WPPSI)
by Weschler, David

Norm referenced
Verbal and non-verbal response mode
Administered individually
Age: 4 - 6.5 years
Administration Time: 60 minutes

This test is designed to measure the verbal and performance abilities of young children. It yields a verbal score, a performance score and a full scale IQ score. It is considered an appropriate IQ test for autistic children, though flexibility in administration is important. Test purchase is restricted.

Psychological Corporation
757 Third Avenue
New York, NY 10017

Wechsler Intelligence Scale for Children - Revised (WISC-R)
by Weschler, David

Norm referenced
Verbal and non-verbal response mode
Administered individually
Age: 5 - 16 years
Administration Time: 60 minutes

This scale is designed to assess children's ability and capacity to cope with the world. It consists of 10 subtests, each of which contains

items that increase in difficulty. Administration yields a verbal score, a performance score, and a full scale IQ score. Although it is considered an appropriate IQ test for autistic children, flexibility in administration is important. Test purchase is restricted.

Psychological Corporation
757 Third Avenue
New York, NY 10017

Tests of Language Development

Carrow Elicited Language Inventory (CELI)
by Carrow-Woolfolk, Elizabeth

Norm referenced
Verbal response mode
Administered individually
Age: 3 - 7 years
Administration Time: 5 minutes

This test diagnoses specific expressive language deficiencies and is designed to measure a child's grammatical performance. By tape recording the child's imitation of a sequence of sentences that increase in difficulty, specific grammatical structures that may be problematic for the child can be identified. Reliability, validity and standardization information are available.

Teaching Resources Corporation
50 Pond Park Road
Hingham, MA 02043

Northwestern Syntax Screening Test
by Lee, Laura L.

Norm referenced
Verbal response mode
Administered individually
Age: 3 - 8 years
Administration Time: 15 minutes

This screening instrument attempts to identify children with delayed syntactic development. It measures both receptive and expressive language levels.

Northwestern University Press
1735 Benson Avenue
Evanston, IL 60201

Peabody Picture Vocabulary Test
by Dunn, Lloyd M.

Criterion and norm referenced

Non-verbal response mode
Administered individually
Age: 1.9 - 18 years
Administration Time: 15 minutes

This test measures the level of receptive language by asking the subject to identify objects on picture cards by gesturing or pointing to the correct answer. Raw scores may be converted to mental age equivalency, intelligence quotients and percentile ranks. This test is useful as a pre- and post- measure for knowledge of simple words. Two forms are available. Reliability, validity and norming information are available.

American Guidance Service, Inc.
Publishers' Building
Circle Pines, MN 55014

Reynell Developmental Language Scales
by Reynell, Joan K.

Norm referenced
Verbal response mode
Administered individually
Age: 1 - 6 years
Administration Time: unknown

This clinical set of scales is designed to assess verbal comprehension and expressive language. It is designed for children with various handicaps and yields standard scores.

Nfer Publishing Company, Ltd.
2 Jennings Building, Thames Avenue
Windsor Berkshire
SL4 IQS Great Britain

Test for Auditory Comprehension of Language (TACL)
by Carrow-Woolfolk, Elizabeth

Norm referenced
Non-verbal response mode
Administered individually
Age: 3 - 6 years
Administration Time: 20 minutes

This instrument is designed to determine the subject's level of understanding of auditory language structures. The examiner presents verbal stimuli and the subject responds non-verbally by pointing to pictures. Four subscales include: form class and function words, morphological constructions, grammatical categories and syntactic structure. The test is available in Spanish and English versions. The test is useful for measuring a child's receptive knowledge of language. Reliability and validity data are available.

Teaching Resources Corporation
50 Pond Park Road
Hingham, MA 02043

The Receptive-Expressive Emergent Language Scale (REEL)
by Bzock, Kenneth R. & League, Richard

Norm referenced
Response format - parent interview
Adminstered individually
Age: questions pertain to birth to 3 years
Administration Time: approximately 30 minutes

The format of this instrument, which involves a parent interview, permits an accurate ssessment of the infant's level of expressive and receptive language skills. It was designed for the early diagnosis of specific organic disorders and for identifying functional learning disabilities. The REEL is especially useful with lower functioning or younger children. Reliability and valididty data are available.

The Tree of Life Press
P. O. Box 447
Gainesville, VL 32601

Utah Test of Language Development (UTLD)
by Mecham, Merlin J.

Norm referenced
Verbal and non-verbal response mode
Administered individually
Age: 1 - 15 years
Administration Time: 30 - 45 minutes

This instrument measures receptive and expressive language skills. Standardization, reliability and validity data are available.

Communication Research Association
P. O. Box 1310212
Salt Lake City, UT 84111

Tests of Behavior and Social Functioning

AAMD Adaptive Behavior Scale
by Nihira, K., Foster, R., Shellhass, M. & Leland, H.

Norm referenced
Verbal and non-verbal response mode
Administered individually
Age: Standard version - age 3 to adult; public school version - grades 2 - 5.
Administration Time: 15 - 20 minutes

This instrument is a behavior rating scale for mentally retarded, emotionally maladjusted and developmentally disabled individuals. It is designed to provide objective descriptions and evaluations of an individual's adaptive behavior levels. The results provide ratings in 24 areas in 2 parts:

1.) Adaptive behavior - 10 domains relating to developmental abilities (personal independence)
2.) Maladaptive behavior - 14 domains

American Association on Mental Deficiency
5101 Wisconsin Avenue N. W.
Washington, D.C. 20016

Behavior Characteristics Progression (BCP)
by The Office of the Santa Cruz County Superintendent of Schools

Criterion referenced
Non-verbal response mode
Not "administered"
Age: 0 - 6 years

This booklet provides descriptions of 2400 behavioral characteristics in the following developmental areas: gross motor, fine motor, cognitive, receptive language, expressive language, social behavior and self-help. The characteristics are grouped into 59 strands containing identifying behaviors that are helpful in developing teaching programs after identifying functioning levels.

VORT Corporation
P. O. Box 11132
Palo Alto, CA 49306

Behavioral Rating Inventory for Autistic Children and Other Atypical Children (BRIAAC)
by Ruttenburg, A., Kalish, B. I., Wnar, C., Wolf, E. G.

Norm referenced
Non-verbal response mode
Administered individually
Age: 1 month - 4.5 years
Administration Time: 2.5 hours

This instrument is designed to provide a thorough assessment of a child's functioning in these areas: relationship to an adult, communication, drive for mastery, vocalization and expressive speech, sound and speech reception, social responsiveness, body movement and psychobiological development. The child's behavior is observed and scored (1-10) with the help of descriptive examples that illustrate each level. The BRIAAC is useful for assessing the functional levels of children who are "difficult to test" and aids in developing educational plans since it suggests sequential developmental steps in the eight areas it covers. Reliability and validity data are available.

Stoeiting Company
1350 S. Kostner Avenue
Chicago, IL 60623

Vineland Social Maturity Scale
by Doll, Edgar A.

Norm referenced
Non-verbal response mode, interview format
Not "administered"
Age: 1 month - 25 years
Administration Time: 20 - 30 minutes

This scale, which may be completed by parent interview, is useful in assessing a child's ability to be responsible for his own needs. The eight areas covered are: self-help, eating, dressing, locomotion, occupation, communication, self-direction and socialization. It gives valuable information concerning levels of functioning and development of the autistic child.

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ETIOLOGY

Since its discovery by Kanner in 1943, researchers have attempted to determine the cause of autism. After almost forty years of research, the specific cause or causes of the syndrome are still unknown, although evidence to date supports multiple causation. Various factors have shown themselves significantly involved in contributing to the symptomology of the disorder, yet no one factor stands out as a major cause.

Historically, initial studies pursued a theory of psychological causation. Although he later refuted his statement, Kanner originally stated that these children had highly intelligent, undemonstrative parents and had suffered "life experiences that confused them and drove them to withdrawal and schizophrenic behavior". Bettleheim was a strong supporter of the theory of maternal deprivation or "refrigerator parents". DesLauriers and Carlson theorized that deficient human stimulation and environmental stimulation were the causal factors in autism. Tustin suggested two forms of autism in 1973: primary, which results from a lack of nurturing, and secondary, which results from the trauma of being separated from the mother too early in life. However, these theories are generally unsupported by research. Although there are conflicting reports on the intelligence and social class level of parents of autistic children, there is virtually no evidence that autism is an emotional disorder with a psychogenic basis.

There is strong evidence that autism has a biogenic origin. Various forms of neurological dysfunction are associated with autism as are some conditions that produce central nervous system impairment. In addition to neurological factors, the early onset of autism suggests a biological origin. The research in this area abounds. In order to summarize most efficiently, Paluszny's review of three of the most active and promising areas of research will be discussed: genetic, biochemical and viral.

Genetic studies performed by Folstein & Rutter (1978) on twenty-one same sexed twins, in which at least one twin was autistic, indicated the possibility of a genetic predisposition which may operate on its own or in combination with other biological hazards in the perinatal period. This research and other results estimate that there is a two percent chance of any one sibling having autism in a family where one child is autistic.

Extensive biochemical studies have also been completed. In 1974 Coleman performed various tests on a large group of autistic children. Two significant findings were made. First, the autistic parents were found to have had a very unusual exposure to chemicals, significantly higher than the control parents. Second, the autistic parents had a significantly higher presence of hyperthyroidism in the preconception history. Eleven studies have shown autistic children to have higher levels of serotonin, a neurotransmitter necessary for brain function. This is particularly interesting, since low levels have been observed in hyperactive children, and increasing the levels have resulted in more normal behavior.

Unfortunately, the results are inconclusive; chemically descreasing serotonin levels has improved behavior in some children and has not in others. Also, studies reveal that approximately one-third of severely mentally retarded children who are not autistic also have increased serotonin levels. Another conflicting problem is the fact that some autistic children have low serotonin levels. One study showed observed improvement in behavior, sleeping habits and attention span when they were given high doses of vitamin B-6, which elevates sertonin levels. Still another subgroup of autistic children have elevated amounts of uric acid in the urine, and some have increased fat in the stools, which is associated with celiac disease. It is important to note that many of these studies are, as of yet, unreplicated. Still, it is apparent that various factors may be contributing alone, or in conjunction with other factors, to several types of autism.

Investigations into the effects of viral infections that are contracted during pregnancy have shown that rubella (german measles) can cause CNS damage and may be related to autism. Studies by Peterson and Torrey found evidence of herpes encephalitis in parents of autistic children. Coleman notes that the temporal lobe, the portion of the brain that processes language, is the portion of the brain that is attacked by the herpes virus if there is encephalitis. One Boston study showed evidence of "somewhat diminished" temporal lobes in the autistic subjects. As yet, no conclusions can be made about the role of viral infections in causing autism. Further study is needed in this area.

Most recently, several new etiological theories are being examined. One of these supports the hypothesis that autistic children have a damaged left hemisphere and so are operating with only the right hemisphere of the brain. A Canadian study about body proportions found that the left side of autistic children's bodies were significantly larger. Another study which examined hemisphere size, found that although normally the left hemisphere is most often larger, in 57% of the autistic children studied, the right hemisphere was larger in size. However, these findings were not confirmed in another study and have been associated with "dyslexic" children also.

Another interesting area of research theorizes that autism results from some abnormal experience that takes place in the womb, probably during the second trimester when the central nervous system (CNS) formation is completed. This theory is supported by a study of mothers of autistic children who reported bleeding during their second trimester of pregnancy. There is also evidence that autistic children exhibit slight physical space between their toes, and under- or over-developed bone structures.

In an attempt to summarize the consensus of opinion on the etiology of autism, it appears that although no specific cause is yet known, much progress has been made. Most view autism as an organic disorder of some type, caused by central nervous system impairments. This impairment could be caused by one or several contributing factors. It is also possible that there are several kinds of autism, with overlapping causes. No one cause

may ever be found, although surely knowledge about the cause of this syndrome will increase and be refined as more research is done, testing and eliminating possible contributing factors. It is most crucial at this point to continue, and promote more research with autistic persons, so that they and the syndrome itself can be better understood.

SUGGESTED READING:

Coleman, M., M.D. New research findings and concepts in autism. Presented at the National Society for Autistic Children's Annual Conference, 1979. In this paper, Coleman presents her research into the cause of autism. The majority of this information is from her book, "The Autistic Syndromes", published in 1974. Presented with less technical jargon, this paper is interesting and understandable.

DeMyer, M. K., Barton, D., DeMyer, W. E., Norton, J. A., Allen, J. & Steele, R. Prognosis in autism: A follow-up study. Journal of Autism and Childhood Schizophrenia, 1973, 3, 199-216. This study followed-up 85 autistic boys and 35 girls for an average of 6.1 years. Prognosis for recovery for autistic was presented as follows: 1-2% normal lives, 5-15% borderline, 16-35% fair, and 65-75% poor. Forty-two percent of the sample had been institutionalized. The best predictors of a good prognosis were found to be social adaptation and ability to function at the time of intake. The authors support an etiological hypothesis of autism as an organically based language disorder plus a perceptual-motor disorder which hinders acquisition of both verbal and non-verbal communication skills.

DesLauriers, A. M. The cognitive-affective dilemma in early infantile autism - The case of Clarence. Journal of Autism and Childhood Schizophrenia, 1978, 8 (2), 219-232. This case study presents long-term follow-up data on Clarence, one of Kanner's original cases of infantile autism. Clarence's attempts to establish and maintain social relationships is described, including his marriage plans. The case study is seen as supportive of DesLauriers and Carlson's (1969) theory that a disturbance of affective contact is the major problem in infantile autism.

Ornitz, E. M. The modulation of sensory input and motor output in autistic children. In Psychopathology and child development: Research and treatment. New York and London: Plenum Press, 1976, 115-133. This article explores several possible explanations for the autistic child's observed unusual motility disturbances. The author suggests that the autistic child may be attempting to "make sense" of the many sensations he experiences in the environment by sensorimotor feedback (hand-flapping, spinning and flipping, etc.).

Paluszny, M. J., Etiology. In Autism: A practical guide for parents and professionals. Syracuse: Syracuse University Press, 1979. This chapter is one of the most comprehensive, well written, and understandable of the references reviewed about etiology. Psychogenic theories are discussed briefly before the author tackles the task of presenting the many biogenic theories.

The discussion is organized, straightforward, and lacking the bias and jargon of many medical authors.

Schopler, E. Changes of direction with psychotic children. In A. Davids (Ed.), Child personality and psychopathology: Current topics (Vol. 1). New York: Wiley, 1974, 1974. 205-236. This chapter traces some of the sources of past confusion regarding etiology and treatment of autistic children, including the shift from theoretical beliefs to more specific information from current research. It summarizes the current state of affairs and projects future trends based on TEACCH research and clinical experience.

Sullivan, Ruth C. Hunches on some biological factors in autism. Journal of Autism and Childhood Schizophrenia, June, 1975, 5(2), 177-183. The author speculates on the implications of the increasing number of families who report diagnosed rheumatoid arthritis and related conditions. The reported information suggests questions for future research, mainly, the relation between autism, rheumatoid arthritis, celiac disease and possibly depression.

OTHER SUGGESTED READING:

Coleman, M. A report on the autistic syndrome. In Michael Rutter and Eric Schopler (Eds.), Autism: A reappraisal of concepts and treatment. New York: Plenum Press, 1978, 185-199.

Coleman, M. (Ed.) The Autistic Syndromes. Distributed by the National Society for Autistic Children, Washington, D. C., 1976.

Folstein, S. & Rutter, M. A twin study of individuals with infantile autism. In Michael Rutter and Eric Schopler (Eds.), Autism: A reappraisal of concepts and treatment. New York: Plenum Press, 1978, 219-241.

Rimland, B., Calloway, E., & Drefus, P. The effect of high doses of vitamin B6 on autistic children: A double-blind crossover study. American Journal of Psychiatry, 1978, 135(4), 472-475.

Rimland, B. Inside the mind of the autistic savant. Psychology Today, August, 1978, 69-70; 73-74; 77-80.

Rosenblum, S. M., Arick, J. R., Krug, D. A., Stubbs, Young, N. B., & Pelson, R. O. Auditory brainstem evoked responses in autistic children. Journal of Autism and Developmental Disorders, 1980, 10(2), 215-225.

Ritvo, E. R., Rabin, K., Yuwiler, A., Freeman, B. J., & Geller, E. Biochemical and hematologic studies: A critical review. In M. Rutter & E. Schopler (Eds.), Autism: A reappraisal of concepts and treatment, New York: Plenum Press, 1978.

Rutter, M. Etiology and treatment: Cause and cure. In M. Rutter and E. Schopler (Eds.), Autism: A reappraisal of concepts and treatment, New York: Plenum Press, 1978.

EDUCATION AND TREATMENT

Research results and follow-up studies have suggested that the provision of special schooling for autistic children is associated with scholastic and social benefits. Autistic persons can benefit from formal education. The massive amount of research supports the view that not only behavior management but also profitable educational learning can be achieved by adopting a structured learning environment compatible with the individual needs and learning patterns of the child. Integrating the child's unique circumstances and the life style of the family aids in making the learning environment as consistent as possible. It is generally agreed that it is most advantageous in terms of generalization of learning, not to mention maintaining the sanity and stability of the family, to involve family members in the education and treatment of the autistic child. Parent training is considered to be an integral component of the continuum of services for autistic children. The parent's needs and desires for their child should be examined before behavioral treatment plans are made, and all educational and behavioral treatment plans should be discussed with parents at the onset.

Although there is much variation in the manner in which it is stated, there is little argument concerning the goals of educating persons with autism. It may be stated in any of these ways: "to create successful experiences for autistic persons"; "to reach the optimal level of independent functioning"; "to help the handicapped person get as much out of life as possible"; "to give autistic people a chance".

The translation of the goals into educational methods is a more difficult task. Lovaas' extensive work in behavior modification and learning theory techniques as used with autistic children has been highly successful and has been replicated in numerous other studies. In fact, although techniques have been greatly refined and specialized, the behavior modification approach to teaching autistic children is, to date, the most widely used approach. This approach involves positive reinforcement of appropriate behaviors and ignoring or punishing inappropriate behaviors in a systematic and consistent manner. In this way, the child learns to associate positive experiences with appropriate behaviors, performs these behaviors more frequently, and so, learns the desired behaviors. Meanwhile, the inappropriate behaviors occur less frequently. With regard to negative behaviors, research into alternatives to punishment has been so productive that harsher forms of punishment are often considered unethical and only "last-resort" measures.

Recently, several comprehensive manuals have been published dealing with educating autistic children. One such manual developed by the Project Educate Staff of Indiana University, stresses the importance of making the environment conducive to learning by reducing the controllable interferences to learning. The authors state that "kids must feel liked; they must feel trust". Many features of an educational environment can be altered to create the most trusting, caring environment. For example, by organizing a structured, tidy room with well-defined work and play areas,

children's relaxation and confidence levels can be increased. Acceptable and unacceptable behaviors need to be well-defined as well as consequences for performing those behaviors. Consistency, routine and structure are all needed to maintain the children's trust. Most important, the children's needs must be met and safe, allowable outlets provided for behaviors that are their means of coping.

The curriculum content of programs for persons with autism has received much attention in the literature. It is questioned whether or not the normal developmental sequence necessarily provides the best basis for deciding what to teach. An assessment tool recently developed deals with this issue by measuring, not only skills developed and undeveloped, but also "emerging" skills. These emerging skills are then written into the child's educational plan so as to provide for the most successful learning experience possible. The content areas acknowledged to be essential in a curriculum for autistic individuals are self-help skills, language training, behavior management, motor development followed by academic skills, pre-vocational, and vocational skills for the higher functioning adolescent.

Four service delivery trends, according to Paluszny, are currently strongly affecting the direction of education for autistic children. These four concepts relate to the integrity of service delivery and educational responsibility. Normalization refers to the philosophy that the handicapped should live their lives as close to "normal" as possible. For children who live in residential facilities especially, this concept is most important. Evidence of a "normalized" environment might include a home-like living area, meals served family style, and facility centered laundry and food services.

The deinstitutionalization movement began several years ago when the reality of poor conditions and lack of client progress in the institution became public knowledge. Attempts are presently being made to improve the situation by preventing institutional placements, returning those presently placed in institutions to their communities and improving the conditions of the institutions.

Mainstreaming is the public school equivalent of deinstitutionalization. It refers to the gradual movement of children from segregated special education classrooms to regular classrooms or some equivalent. The autistic child's specialized educational needs and characteristics lack of response to group instruction exhibited by most young autistic children make mainstreaming a questionable alternative in the majority of cases.

Finally, service integration is needed for any of these concepts to be employed, since all require the effort of people working at various levels in various organizations. The multidimensional nature of the problem of autism necessitates community effort, and since most human service agencies do not normally share information or work together in any way, service integration is very difficult to achieve. Many attempts at service integration are underway, though, including regional training and service centers and community outreach programs. Parent groups are essential to

to the promotion of service integration for they are a group that have a first-hand interest in the education and treatment right of their children. In recent years, parents have promoted legislation supporting their children's rights to ideals that demand service integration.

In spite of the wealth of literature relevant to the education of the adult population, and the recent publication of a few manuals concerned with the vocational needs of adolescents and adults, more research is needed in this area. Part of the problem may stem from the lack of available service alternatives, although more and better services are becoming available as more is learned about the service needs of the adult age group.

SUGGESTED READING:

DeMyer, M. K. The nature of the neuropsychological disability in autistic children. In Psychopathology and child development: Research and treatment. New York and London: Plenum Press, 1976, 93-114. In this study, 66 autistic children are compared to a group of 20 "subnormal" children to see what differentiated the two groups. Results indicated that the autistic children had the most difficulty with tasks that required integrating skills and memory skills. Higher functioning children appear to benefit the most from treatment.

Landing, M., & Schopler, E. Individualized education: A public school model. In M. Rutter & Schopler (Eds), Autism: A reappraisal of concepts and treatment. New York: Plenum Press, 1978, 439-452. A discussion of the need for individualizing educational curricula for autistic children is presented. Methods of implementating this process are suggested, including proper assessment of the autistic child's unique strengths and weaknesses and parental involvement in the educational process. Division TEACCH is cited as a model for developing administrative structures to facilitate needed individualization.

Lovaas, O. I., Schreibman, L., & Koegel, R. L. A behavior modification approach to the treatment of autistic children. In Psychopathology and child development: research and treatment. New York and London: Plenum Press, 1976, 291-310. In this article, the author describes the usefulness of behavior modification techniques when used with autistic children. Recent techniques for dealing with self-destructive behaviors and self-stumulatory behaviors are discussed, along with techniques for teaching appropriate behaviors and building language. This article may be helpful for teachers in early program planning.

Schopler, E. Towards reducing behavior problems in autistic children. In L. Wing (Ed.), Early childhood autism (2nd Ed), New York: Pergamon Press, 1976, 221-245. Some relationships between historical assumptions of autism as "response to family stress" and parental difficulties in managing their autistic child are identified. Specific versus general management difficulties are distinguished. Suggestions are made for helping parental management through changing treatment structures.

Schopler, E., Brehm, S., Kinsbourne, M., & Reichler, R. Effect of treatment structure on development in autistic children. Archives of General Psychiatry, 1971, 24, 415-421. To assess the impact of structure variation on the treatment of autistic children, a study was designed in which structure was changed from relative structure to relative unstructure over two repeated cycles of two weeks each. Both children and therapists were rated on their reactions. Findings indicated that autistic children tended to react more favorably to structure than to unstructure.

Schopler, E., & Olley, J. G. Public school programming for autistic children. Exceptional Children. 1980, 46, 461-463. Eight components of a comprehensive educational program for autistic children were identified. These components are (a) a system of identification and referral, (b) assessment which leads to an educational program, (c) parent involvement, (d) an individualized instructional process, (e) agency cooperation, (f) staff training, (g) regional administration, and (h) a university tie.

Schopler, E., Reichler, R. J., & Lansing, M. Individualized assessment and treatment for autistic and developmentally disabled children: Volume II, Teaching strategies for parents and professionals, Baltimore: University Park Press, 1980. This manual, written for teachers and clinicians, emphasizes a home teaching approach. It shows how to use assessment data to write individualized programs for teaching behavioral and educational tasks. Teaching sessions are well organized and task analyzed, and materials suggested for each task. This very thorough analysis of a successful educational approach should be helpful to anyone who teaches autistic children.

Wolthuis, Ronald M. Meeting the special needs of children with autistic characteristics. University of Minnesota Advanced Training Institute, May 21-26, 1978. This article lists and describes eight elements for comprehensive program development for severly emotionally impaired/ autistic. It describes 11 professionals needed for quality programming and what should be included in a comprehensive personnel training program. It discusses concerns regarding "lack of information sharing", "the need for state and regional program planning and coordination", "lack of standards for personnel preparation", and the "need for coordination between different disciplines". A bibiography on autism including audiovisual references, and names and addresses of training programs in autism is included.

OTHER SUGGESTED READING:

Donnellan-Walsh, A., Gossage, L. D., LaVigna, G. W., Schuler, A. L. & Traphagen, J. D. Teaching makes a difference, Baltimore: University Park Press, 1981. Educating Autistic/Severely Handicapped Children Elementary Age. Developed by Project Educate Staff of Indiana University Developmental Training Center. Indiana: Indiana University Developmental Training Center, 1980.

Hemsley, R., Howlin, P., Berger, M., Hersov, L., Holbrook, D., Rutter, M., & Yule, W. Treating autistic children in a family context. In Rutter, M. & Schopler, E. (Eds.), Autism: A reappraisal of concepts and treatment. New York: Plenum Press, 1978.

Paul, J. L. & Posante-Loro, R. Educational responsibility. In J. J. Paluszny (Ed.), Autism: A practical guide for parents and professionals. New York: Syracuse University Press, 1979.

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COMMUNICATION

Language impairment, receptive and expressive, and communication problems, verbal and non-verbal, are the primary and most frequently observed characteristics of autism. Language disabilities minifest themselves not only by a lack of verbal language, but also affect non-verbal aspects of communication such as facial expressions, gestures, and body language. Language abilities are an important prognostic indicator; in terms of adjustment, those who have developed language by the age of 5 have a better adjustment during later years. Overall, autistic persons exhibit a lack of understanding of the process and function of language for communication.

Those who have verbal speech may be echolalic and repeat what is heard spoken by others in a meaningless manner. Sometimes the echolalia serves a purpose for the child, so that a child who associated receiving a drink when asked, "Do you want water?", may ask "Do you want water?" in order to get a drink on another occasion. For another child, echolalic speech may be used as a means of self-stimulation. Other verbal children may have reverse pronoun usage, indicating a lack of the abstract concepts "you, me, my, your, and I". Verbal children have problems with sentence construction or "tying" concepts together. They may mimic or speak with strange voice intonations, or mechanically.

Receptive language is, in some children, more advanced than expressive language. On the other hand, some children may be able to read words, but be unable to understand what they have read. Unlike deaf children, those with autism do not attempt to compensate for their disability by developing other means of communication such as gestures. This apparent lack of motivation to communicate socially or otherwise has raised questions concerning the cause of these serious language impairments. Another striking feature of autistic children's language is the lack of reciprocity, that is, they rarely converse in a normal "back and forth" manner.

Researchers have noted that the language of mute autistic children usually takes one of two courses; either the child never spoke at all, or developed speech normally to a point, ususally age 2-3, and then totally stopped speaking. As to the latter case, one researcher has suggested that since before the age of 2, most speech is simple echoing, and after age 2 children begin to apply meaning to these words, perhaps the autistic child's problem lies in his inability to cognitize or recognize the relationship between objects and spoken words. Research has shown that these children have particular problems learning classification words, that is, apples, bananas, oranges are all fruits. The research of Wolff and Chess; Rimland, Hermelin and O'Connor; Rutter and Bartak, and Baltaxe and Simmons all indicate some type of cognitive inability of the autistic child to comprehend and "process" language.

The language defect can manifest itself in any child in many varied ways, stressing the importance of an accurate, thorough assessment of a

child's language level before attempting to plan an educational language program. Schopler, Reichler and Lansing discuss several important considerations in the language assessment. First, never make assumptions about language skills without testing the skills out in several situations. The examiner should give the child varied cues - verbal, gestural, situational - so that all aspects of his receptive abilities are tested. Also, the examiner should record the child's spontaneous speech, and observe speech patterns that may be being used to test expressive language.

After assessing the child's level of understanding, a language program can be developed. Lovaas was successful in developing a technique for teaching speech based on the principles of operant conditioning. Several studies have been completed to determine the usefulness of sign language, verbal language and their combination in teaching children. Sign language may be most helpful for those with a high receptive language level and low expressive language level, but it is generally not suggested for those children who have good verbal imitation skills. More recently, Creedon and others have advocated sign language techniques for use with those who have autism.

In conclusion, considering the extent of language impairments found in all autistic children, it appears that this aspect of autism warrants strong consideration. Because impairments vary greatly, individualized assessments are important before developing educational programs. Several non-verbal language systems have been used successfully and have important advantages for autistic children and their parents, although research results are not yet conclusive as to the most effective techniques for teaching languages.

SUGGESTED READING:

Carr, E. G. A program for establishing sign language in developmentally disabled children. In Lovaas, O. I., Ackerman, A., Alexander, D., Forestone, P., Perkins, M., & Young, D., (Eds.), The me book: Teaching manual for parents and teachers of developmentally disabled children. Baltimore: University Park Press, 1980. The author presents the basic philosophy for teaching sign language to autistic and developmentally disabled children, along with an interesting discussion of the advantages of using sign language with this population. The majority of the chapter presents a program for teaching expressive sign language to an autistic child.

Eisenburg, L. The autistic child in adolescence. American Journal of Psychiatry, 1956, 112, 607-612. In this follow-up study of 63 diagnosed cases of autism, it was shown that language is an important prognostic indicator. The investigators found that 16 of the 32 children with useful speech achieved a fair to good social adjustment, whereas only one of the 31 non-verbal children achieved a fair to good adjustment.

Fay, W. H. & Schuler, A. L. Emerging language in autistic children. Baltimore: University Park Press, 1980. This book, the fifth in the Language Intervention Series, documents the relevant literature

pertaining to the language and communication disorders of autistic children. The authors consider in detail research related to the nature of the language problems exhibited by autistic children and the implications for teaching language and communication to this population. This comprehensive, interesting, and well-written book is important reading for speech therapists or anyone teaching communication to these children with autism.

Lord, K. & Baker, A. Communicating with autistic children. Journal of Pediatric Psychology. 1978, (2), 181-186. The delayed and disordered language of autistic children as it affects the delivery of health care and other services in the inter-disciplinary settings is discussed. Current research is reviewed concerning communication-related deficits. Methods for communicating with autistic children in health care settings are presented.

Rutter, M. Language disorder and infantile autism. In M. Rutter and E. Schopler (Eds.), Autism: A reappraisal of concepts and treatment. New York: Plenum Press, 1979, 85-104. This article describes extensively the research concerning the language impairments in children with autism. The nature of the cognitive impairment that the literature supports is considered along with the boundaries of language deficits. The hypothesis of a link between the language disorders in autism and "dysphasia" is discussed.

Simon, N. Kaspar Hauser's recovery and autopsy: A perspective on neurological and sociological requirements for language development. Journal of Autism and Childhood Schizophrenia, 1978, 8(2), 209-217. This article presents the case study of a 19th century European child who suffered prolonged isolation during childhood and then later learned language. The implicit contradiction of the notion of a critical period for language development in autistic children is discussed.

Swisher, L., Reichler, R. J., & Short, A. Language development history and change in autistic children. In S. K. Hirsch, D. H. Eldridge, I. J. Hirsch, and S. R. Silverman (Eds.), Hearing and Davis: Essays honoring Hallowell Davis. Saint Louis: Washington University Press, 1976. The relationship between early language development and prognosis for autistic children was the focus of this investigation.

OTHER SUGGESTED READING:

Baltaxe, C. A. M., & Simmons, J. Q. III. Language in childhood psychosis: A review. Journal of Speech and Hearing Disorders, 1975, 40 (3), 439-458.

Churchill, D. W. Language in autism. New York: John Wiley & Sons, 1978.

Creedon, M. P. Language development in non-verbal autistic children using a simultaneous communication system. Paper from Society for Research in Child Development, Philadelphia, 1973.

Howlin, P. The home treatment of autistic children. In Hersor, L. A. & Berger, M. (Eds.), Language and language disorders in childhood, Oxford: Pergamon Press, 1980.

Madiera, S. The language of autistic children. In Educating autistic/severely handicapped children - elementary age, developed by Educate Staff of Indiana University, Indiana University Developmental Training Center, 1980.

Rutter, M. Language training with autistic children: How does it work and what does it achieve? In Hersov, L. A. & Berger, M. (Eds.), Language and language disorders in childhood, Oxford: Pergamon Press, 1980.

Schaeffer, B., Kollinzas, G., Musil, A., & McDowell, P. Spontaneous verbal language for autistic children through signed speech. Sign Language Studies, 17, 237-328.

Walker, H. A. Language behavior in a sample from an autistic population. In M. Coleman (Ed.), The Autistic Syndromes. The North Holland Publishing Co., 1976.

Wolff, S. & Chess, S. An analysis of the language of 14 schizophrenic children. Journal of Children Psychology Psychiatry, 1965, 6, 29-41.

SIGN LANGUAGE

The following are references for sign language texts and manuals that are recommended for those persons who work with individuals with autism and are interested in learning sign language or total communication.

Basic Introductory Learning Textbooks:

A Basic Course in Manual Communication
by Terrence J. O'Rourke
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

A Basic Vocabulary: American Sign Language for Parents and Children
by Terrence J. O'Rourke
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

Ameslan - An Introduction to American Sign Language
by Louie J. Fant, Jr.
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

Conversational Sign Language II
by Willard J. Madsen
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

Sign Language
by Louie Fant
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

Sign Language for Everyone
by Jeanne Huffman
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

Signing Exact English
by Jeanne Huffman
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

The Joy of Signing
by Lottie L. Riekehof
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

The Language of Signs
by A. Davis
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

The Signed English Dictionary for Preschool and Elementary Levels
by Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

Textbooks for Teaching Games and Activities:

Play It by Sign
by S. L. Kirehner
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 200[illegible]

Talk with Me
by Jeanne Huffman
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

Textbooks for Teaching Sex-Related Signs

Signs of Sexual Behavior
by James Woodward
Gallaudet College Bookstore, Gallaudet College, Washington, D. C. 20002

FAMILY FACTOR/PARENT INVOLVEMENT

Parents have always been thought to play an important role in the lives of their autistic children. Unfortunately, when the syndrome was first discovered, the primary role considered was a casual one. Much of the original research purported parents, primarily of high social status, to be "cold and aloof", "unemotional", "refrigerator parents". Bettleheim, who saw parents as causing their child's autism, recommended that the child be removed from the parents for treatment. Schopler called this "parentectomy" practice "scapegoating" by professionals.

In the last decade, the role of parents has changed from that of a negative one to a positive role that is viewed as essential to the child's educational and behavioral progress. Bristol and Wiegerink note three trends that have resulted in this changing role: 1.) increasing evidence of a biological basis for autism, 2.) lack of empirical support for psychogenic theories, and 3.) the development of behavioral interventions. Widespread acceptance of behavioral techniques as effective for use with autistic persons has aided in increasing parental involvement in their children's treatment since these techniques are relatively straightforward and can be taught rather simply. Present trends advocate parental involvement in all aspects of the treatment program. Increasing the parent's involvement aids the professional as well as the parents. Lovaas reported the results of a study showing that children whose parents were trained to carry out behavior therapy continued to improve after discharge while children in institutions with untrained parents regressed. Marcus states that dealing with parent's shock at the reality of the situation is never as unpleasant as dealing with the confusion that results from professionals' attempts to "protect" the parent. Thus, it appears more helpful for parents and professionals alike to work together and for both reap the benefits of that relationship. For example, by observing one another during treatment sessions, both can make suggestions that may increase the successfulness of the sessions and be assured that they are carrying out the sessions in a consistent manner. Also, by determining the parent's priorities for treatment, the professionals can assist the parent to achieve objectives which will result in a happier home life for the entire family. Parents, in turn, can assist professionals by providing feedback to the professionals during sessions, since the parent is the expert on his or her child. Finally, the professional can help the parents develop realistic expectations so that they may enjoy a feeling of accomplishment and success at even the smallest gains made by their child.

It must be remembered by the parents and professionals alike that parents are individuals too. Parents must avoid becoming so involved in their child's welfare that they lose a sense of themselves; instead, they must achieve a balance of concern and love for their autistic child with their own individuality. Though professionals can aid parents in achieving a realistic picture of their child's future and what that means for them, ultimately the responsibility lies within the parent to maintain his or her individuality and personhood.

SUGGESTED READING:

Davis, S., & Marcus, L. M. Involving parents in the treatment of communication-disordered children. Journal of Pediatric Psychology, 1980, (5), 189-198. Methods and activities for working with parents of severely communication-disordered children are presented. Emphasis is placed on directly involving parents in the treatment process. The authors argue that language handicaps should be viewed in a broad social context. Parent's concerns and priorities should be incorporated in planning for the child.

Marcus, L. M. Patterns of coping in families of psychotic children. American Journal of Orthopsychiatry, 1977, (47), 388-399. The nature of family adaptation to severely and chronically disabling cognitive and behavioral conditions is considered. The relationship between atypical development and family response is examined to derive basic concepts - parents' perceptions of their child's unusual characteristics, effects on social relationships, etc. - and suggest strategies for intervention and research.

Park, Clara C. You are not alone. Boston: Little, Brown & Co., 1976. This book is "a guide for families of the mentally ill." Written by the mother of an autistic child, it contains a wealth of information for families in crisis, including definitions of mental illnesses and treatments, with chapters discussing what the community offers, how to consult professionals and choose mental health facilities and practical matters that must be considered. A particularly useful chapter deals specifically with the critical issues involved in having a mentally ill child. This extremely interesting book is written with the sincere conviction of a parent who has suffered, searched, and finally learned that she is not alone.

Schopler, E. Changing parental involvement in behavioral treatment. In M. Rutter & E. Schopler (Eds.), Autism: A reappraisal of concepts and treatment, New York: Plenum Press, 1978, 413-421. The history of two important shifts in the treatment of autistic children is discussed. One is the shift of parent as a causative factor to parent as an effective treatment agent; the other is the development of therapeutic treatment approaches derived from behavior modification techniques.

Schopler, E. Collaboration with parents of autistic children. In L. E. Arnold (Ed.), Helping parents help their children: A handbook for professionals who guide parents. New York: Bruner/Mazel, 1978. This paper describes the important role of parents as co-therapists in working to help their autistic children. Factors stressed as important are complete openness with the family, consideration of their needs, and collaboration in considering long and short term goals and expectations for the child.

Schopler, E. Limits of methodological differences in family studies. In M. Rutter & E. Schopler (Eds.) Autism: A reappraisal of concepts and treatment, New York: Plenum Press, 1978, 413-421. It is argued that methodological problems alone cannot account for disparities of findings in the literature regarding family influence on autism. It is further suggested that psychoanalytic theory, explaining normal and deviant personality development as a function of early family experience, led to the "fad hypothesis" of parents as etiologic factors in childhood autism.

Schopler, E. Parents of psychotic children as scapegoats. Journal of Contemporary Psychotherapy, 1971, (4), 17-22. The purpose of this paper is to examine some of the conditions and reasons why parents of autistic and psychotic children have been regarded as primary agents in their child's psychosis, and to consider whether the age-old mechanisms of scapegoating may be in operation.

OTHER SUGGESTED READING:

Cantwell, D. P., Baker, L. & Rutter, M. Family factors. In M. Rutter & E. Schopler (Eds.), Autism: A reappraisal of concepts and treatment. New York: Plenum Press, 1978, 413-421.

Schopler, E., & Reichler, R. J. How well do parents understand their own psychotic child? Journal of Autism and Childhood Schizophrenia, 1972. (2), 387-400. To test the hypothesis that parents can assess their psychotic child's level of development accurately, parents of 47 children were asked to estimate their child's level of functioning in several developmental areas. Their estimates were compared with those based on standard psychological testing. Parental estimates correlated significantly with test-based estimates. Parents whose children were mildly psychotic were relatively poorer estimators than of moderately or severely psychotic children.

Hemsley, P., Howlin, P., Berger, J., Hersov, L., Holbrook, D., Rutter, M., and Yule, W. Treating autistic children in a family context. In M. Rutter and E. Schopler (Eds.), Autism: A reappraisal of concepts and treatment, New York: Plenum Press, 1978, 379-411.

Bristol, M. & Wiegerink, R. Parent involvement. In Maria J. Paluszny (Ed.), Autism: A practical guide for parents and professionals, New York: Syracuse University Press, 1979, 131-147.

Wing, L., M.D., D. P. M. What parents can do. In Autistic children: A guide for parents and professionals, New Jersey: Brunner/Mazel, Inc., 1972, 58-130.

ADOLESCENCE AND ADULTHOOD

As public knowledge and understanding of the syndrome of autism increases, so does the observed need for services. Fortunately, with increased need has come more and better services. Still, there is an obvious lack of services for adolescent and adult autistic persons, even the literature relevant to their needs is meager. Autistic persons live a normal lifespan despite the severity of their disability; thus, the majority need to be provided for all their lives. A few follow-up studies have been performed over the years that provide some information concerning the prognosis for autistic persons. The conclusions of Lotter's review of follow-up studies indicate that the range of outcome is very wide and that only a small percentage "emerge" from autism to be socially and vocationally independent.

Sloan and Schopler summarized the major conclusions of the available literature: 1.) the majority of autistic people have retarded intellectual abilities, many with IQ scores of 70 or less; 2.) it appears that no more than 5-15% of those studied achieved a "good" outcome and 50 - 80% were at home or institutionalized; 3.) about 50% developed language, and the development of language improves prognosis; 4.) many had or developed some organic impairment; and, 5.) probably no more than 5% have had employment experience. The last statement may be a bit pessimistic; other research indicates that 40% of those with an IQ above 70 do gain employment, and 0% of those with an IQ below 50 successfully gain employment.

Several other factors point out the most logical direction for services for adolescents and adults. First, the prohibitive cost of long term private care has made it impossible for the average family to consider this an option. Second, state institutions have demonstrated that they do not offer the specialized services that are essential for autistic persons. Third, since quality parent training has become more available, families are more anxious to become involved in helping with their child's education and treatment. However, the physical size and sexual maturity of the adult age group limits even the most caring family's ability to live with the adolescent or adult. Finally, increased community understanding and acceptance of handicapped people has made the community an alternative for serving the older autistic persons.

It is evident that group homes, allowing increased independence, a maximally "normalized" environment and a chance to gain meaningful employment, are a viable service alternative. Several of the more reputable service providers in the country are developing group homes. These homes may provide education within the home itself or utilize a nearby special education school or vocational school. The majority of sheltered workshops do not offer the supervision necessary to deal with an autistic individual's problem behaviors and the need for frequent reinforcement. Therefore, a more "self-contained" approach to teaching pre-vocational and vocational skills is most frequently implemented with autistic adolescents that maximizes community integration, participation in community affairs and utilizes volunteers from the community.

In summary, the needs of older autistic persons are as variable as those of younger children. Group homes have been established successfully that encourage the most fulfilling life possible, and at a cost that is less prohibitive than that of state institutionalization. More study is needed to explore alternative living situations, with the result that research in this area will probably abound in upcoming years. The problem of autism does not disappear or even lessen after childhood, and it is the responsibility of all to plan for the futures of these children who do have the potential to be contributing citizens of our communities.

SUGGESTED READING:

Everard, M. P. Mildly autistic young people and their problems. Presented at the International Symposium on Autism at St. Gollen, Switzerland, 1976. In this paper the author describes the characteristics of mildly autistic adolescents. She describes how their differences make their lives very difficult with regard to social communication with others, employment, and living independently. Their parents often suffer more anxiety than parents of the more severely handicapped. The author ends with a statement about the needs for the future for this group of individuals.

Lettick, A. L. On Growing-up and away. A position paper prepared for the National Society for Autistic Children, 1974. This paper indicates NSAC's support for families of handicapped persons (and the individuals themselves) to have the right to alternatives. This position paper also advocates training in the least restrictive environment in order to achieve most fulfilling life possible for the handicapped and their families. Available from NSAC, Washington, D. C.

Page, R. Workers who have autism: What you need to forget, what you need to know. Presented at the International Symposium on Vocational Education and Placement of Hard-to-Train Youth. Michigan: September 29, 30 and October 1, 1980. This interesting paper reviews the characteristics of the autistic adolescent and how the adolescent differs from the autistic child. It discusses vocational alternatives and ways to maximize chances for successful job placements, and, as such, represents a useful resource for potential employers and those working with autistic teenagers. Available from NSAC, Washington, D. C.

Sloan, J. L. Autism and the differential residential needs of the autistic population. Presented to Michigan Society for Autistic Children, Kalamazoo, Michigan, November 30, 1979. This article reviews the literature concerning the characteristics and needs of autistic adolescents. Outcome for the adolescent population is discussed with regard to the literature available currently. The Triad Home for Autistic Youth, in Greensboro, North Carolina is described; its residents; their needs and how they are being met; and precautions taken to insure successful functioning of the home itself. Cost of operation information is given also.

Sloan, J. L., & Schopler, E. Some thoughts about developing programs for

for autistic adolescents. Journal of Pediatric Psychology, 1977 (2), 187-190. The concerns of older autistic persons and their families are reviewed, including residential, employment, and social adjustment needs. It is concluded that an individualized intervention program in which parents have primary responsibility for decisions made about their child will prove the most effective and responsive treatment approach.

Showfety, M., Sloan, J. L. Pre-vocational/simultaneous communication classroom for adolescents. New Hanover High School, Wilmington, North Carolina. This article describes one of the four TEACCH classrooms for autistic adolescents in North Carolina. The students and their curriculum are described as are the data collection procedure. The article offers important information for those involved in pre-vocational program planning.

OTHER SUGGESTED READING:

Dewey, M. A. & Everard, M. P. The near-normal autistic adolescent. Journal of Autism and Childhood Schizophrenia, 1974, 4 (4).

Lotter, V. Follow-up studies. In M. Rutter & E. Schopler (Eds.). Autism: A reappraisal of concepts and treatment. New York: Plenum Press, 1978.

Rusch, R. R. & Mithaug, D. E. Vocational training for mentally retarded adults: A behavior analytic approach. Illinois: Research Press, 1980.

Rutter, M. Autistic children: infancy to adulthood. Seminars in Psychiatry, 1970, 2, 435-450.

Rutter, M., Greenfeld, D., & Lockyer, L. Five to fifteen year follow-up study of infantile psychosis social and behavioral outcome. British Journal of Psychiatry, 1967, 113, 1183-1199.

Slaon, J. L. Division TEACCH: Recent program developments and efforts to establish community-based group homes. Presented at the 1977 Annual Meeting and Conference of the National Society for Autistic Children, Orlando, Florida, June 29 - July 2, 1977.

MAJOR TEXTS ON AUTISM[1]

Autism: A Practical Guide for Parents and Professionals
by Maria J. Paluszny, M.D.
New York, Syracuse University Press, 1979

This text presents a multi-disciplinary approach to understanding and teaching autistic children. A Practical Guide for Parents and Professionals is written without technical jargon and is designed to clearly answer the questions of parents and professionals.

Covered in the text are discussions on definition, diagnosis, etiology and a discussion of successful treatment methods for children of different ages and functioning levels.

Autism: A Reappraisal of Concepts and Treatment
by M. Rutter & E. Schopler
New York, Plenum, 1978

This volume presents a review of current knowledge, research, and clinical practice. The contributors, reporting on research conducted in a variety of environments, evaluate many new ideas and concepts in formulating fresh approaches to dealing with the problems associated with autism.

Autistic Children: A Guide for Parents and Professionals
by Lorna Wing
New York, Brunner/Mazel, Inc., 1972

A text that is easily read and understood is a rarity in a field where complex theories and techniques for training are the norm rather than the exception. Lorna Wing has written a thorough definition and explanation of the syndrome of autism as well as a discussion of contributions that doctors, teachers and parents can make toward meeting the needs of this population. Autistic Children has information that is essential for any parent or professional working with autistic individuals, written in a format that is clear and complete.

Benhaven's Manual for Handling Severe Aggression and Self-Abuse
by Amy Lettick, D. H. Davis, S. M. Simonson and L. R. Simonson
Benhaven Press, 1980

The strengths of this manual include appropirate guidelines to consider before planning behavioral interventions, and suggestions which would help to ensure staff and student safety during aggressive episodes. Soft restraint, restraint jackets, startling, time-out or quieting-down rooms are the alternatives specifically covered. The text provides clear justification for restraint and other forms of punishment while at the same time maintaining student and parent rights clearly in the forefront. The weaknesses include a somewhat limited view of options for dealing with aggression or abuse, limited "how to" information, and statements which could be considered biased regarding behavior modification and what is or is not punishment.

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[1]Omission from this list is not intended to imply that a particular text is not of value to the field.

Benhaven's Way
by Amy Lettick
Benhaven Press, 1972

A paper bound collection of lectures given by author Amy Lettick. Benhaven's Way reviews the methods used at Benhaven, a residential school for autistic children and young adults. Included in the lectures are: 1.) a description of Benhaven's children, staffing patterns, teaching and reporting methods and philosophy; 2.) a lecture on structuring teaching sessions; and 3.) a lecture to parents about successful management of the autistic child at home.

Individualized Assessment and Treatment for Autistic and Developmentally Disabled Children, Volume II: Teaching Strategies for Parents and Professionals
by Eric Schopler, Robert Reichler, and Margaret Lansing
Balitmore, University Park Press, 1980

This manual, written for teachers and clinicians, emphasizes a home teaching approach. It shows how to use assessment data to write individualized programs for teaching behavioral and educational tasks. Teaching sessions are well organized and task analyzed, and materials suggested for each task. This thorough analysis of a successful educational approach should be helpful to anyone who teaches autistic children.

Label Me Jeff
by Carolyn Betts
Living and Existing Publishers, 1979

This painfully touching story concerns a boy named Jeff and his mother, who seems to have suffered through the worst of living with an uncontrollable autistic child. Told by Jeff's mother, it is a loving story that deals with her reluctance to put her son in a residential school, although it finally becomes necessary. This book is recommended for everyone who has to work with severely autistic children.

Language of Autistic Children
by Don W. Churhill
John Wiley Press, 1978

Churhill's book on language, a new perspective to teaching autistic children language, is a welcome sight to many who work with autistis children. He presents research indicating a direct relationship between the severity of the autistic impairment and the severity of the language impairment. Also presented is an interesting discussion of the deviant language patterns of autistic children and techniques for teaching language.

Parents Speak Out
by Ann and Rutherford Turnbull
Charles E. Merrill, 1978

This collection of articles by parents of autistic an retarded children, many of whom are also professionals in the field, gives very important insights into the frustrations of working within a

system where educators, mental health workers and physicians frequently have so little or no knowledge about autism or the effects that autistic and/or retarded children have on the family. It is a book that all professionals should read.

Psychopathology and Child Development: Research and Treatment
by Eric Schopler and Robert Reichler
New York, Plenum Publishing Corporation, 1976

A definitive overview of knowledge about severe childhood psychopathology is presented. For the first time, findings of developmental research with normal children are applied to developmental processes in seriously disturbed children.

The Seige
by Clara Park
Boston, Little, Brown and Company, 1972

A mother's well written and sensitive account of family with a girl with the syndrome of autism. The account takes the reader from the child's birth through her seventh year. Because this parent has rare talent as a writer and a special ability to be objective about the experiences of the family, this book should be required reading for any parent or professional working with children in autism. Mrs. Park helps the reader to experience the frustration, embarrassment, the anger and the love created by the child and those in her environment. She shows professionals at their best as well as at worst and shares the benefits of her experiences.

BOOKS FOR CHILDREN

The following are books written for and about children. They may be useful when explaining autism to a peer or sibling of an autistic person or for informing groups of normal school age children about the syndrome of autism.

A Handbook on the Use of Songs to Teach Autistic and Other Severely Handicapped Children
by Lyle Chastain
White Oak Press, 1978

This is a handbook of common children's songs with instructions on how to adapt these songs to teach to groups of autistic and other developmentally disabled children.

He is Your Brother
by Richard Parker
Nelson, 1976

This story, written for the school-aged child, concerns a boy's discovery of his love for his autistic brother. By spending a day with his brother, he sees that he does have interests and can share life with his brother. The story shows how both boys benefit from their "discovery" of one another.

Learning Together
by N. Dalrymple
Developmental Training Center, Indiana University, 1980

This is a booklet narrated by a seven year old named Christy, who describes herself and her own autistic behaviors, in language easily understandable to children at a third grade level. The booklet realistically acquaints youngsters with autism and is thought-provoking and sensitively written.

Please Don't Say Hello
by Phyllis Gold
New York, Human Sciences Press, 1975

It's very difficult to explain to children and neighbors why an autistic youngster does not respond in normal ways. This book, written on an elementary school level in picture book format, is an excellent introduction to a discussion on what it means to be autistic.

Secret Dreamer, Secret Dreams
by Florence Parry Heids
Lippencott, 1978

This fiction book is written for school aged children. It tells the story of a teenaged autistic girl and her family.

The White Colt
by David Rook
Dutton, 1967

This fictional story is written for older teens and adults. It concerns a boy who appears emotionally disturbed and language impaired

and his adventures with a pony he cares for. Their experience together results in growth for the boy in his abilities to relate to others.

MODEL PROGRAMS

The following are programs for persons with autism representing the entire United States. They are well-established and in many cases contribute a considerable amount to the published knowledge about the treatment and education of autistic persons. However, by the use of the title "model programs", the present study does not intend to endorse these programs as models for program development nor to endorse activities that take place in the programs. This list is intended to recognize some existing established programs serving various age groups by various means and to supply a resource for those interested in visiting existing programs or gathering information concerning programming for autistic persons.

Benhaven
9 St. Ronan Terrace
New Haven, Connecticut 06511
(203) 624-9819
Director: Amy Lettick

Number served: 45 day
17 day/residential
Age range served: 6 years - adult
Location: school located in downtown New Haven; residential services on neighboring farm land.

Benhaven is a private, non-profit school for those diagnosed autistic and neurologically impaired. Its philosophy provides for individualized instruction in behavioral, educational pre-vocational, vocational, social and physical skills. Its residential program provides 365-day services. Benhaven also offers consultant services and out-patient programs.

Suggested reading: Lettick, A. L. Benhaven Then and Now, published by Benhaven, Inc., 1979. This volume, which includes the original Benhaven's Way which was published in 1972, provides an update on Benhaven's growth and progress over its eleven year history. Articles and lectures by the author are included.

Division TEACCH
214 Medical School, Wing B, 207H
University of North Carolina at Chapel Hill
Chapel Hill, North Carolina 27514
Director: Eric Schopler

Number served: about 210
Age range served: 5 - 21 years
Location: rural and urban areas through the state of North Carolina.

In 1972, the General Assembly of the State of North Carolina passed legislation creating Division TEACCH, a statewide system of services for persons with autism and related communications handicaps. There are, at present, 5 regional centers, 35 classrooms and 4 group homes serving the children and adults with autism and their parents with the following services: diagnostic evaluation, individualized child therapy, educational instruction in public schools, parent-training and counseling, and parent group activities. Research and professional training are important components of the statewide system, also.

Suggested reading: Marcus, L. M., Semrau, P., & Schopler, E. Division TEACCH: Toward a statewide network of services for the autistic child and his family. Coordinating Office for Regional Resource Centers, Washington, D. C.: August 1977, 34-44. The model for program TEACCH, derived from experience and joint efforts with autistic children and their parents, is presented. Public school integration, parent collaboration, individualization, and a developmental framework are important facets of this program.

Jay Nolan Center
24303 San Fernando Road
Newhall, California 91321
(805) 255-5810
Director: Gary La Vigna

Number served: 24 in group homes
120 in Saturday program
350 in respite care program
Age range served: Adolescents and adults
Geographic location: Various locations in Los Angeles County

The Jay Nolan Center is sponsored by the Los Angeles County Chapter of the National Society for Autistic Children and is operated by an independent board of consumer advocates. At the center of the Jay Nolan philosophy are two concepts: normalization to increase social integration and participation in the community, and use of the developmental model which stresses continuous advancement toward the goals of complete independence and social integration. The Jay Nolan Center's objectives stress a productive learning environment, independence, the provision of support services, and continuing research. The Center's services include 3 adult group homes and one adolescent group home (each serving 6 persons), an in-home respite care program, a Saturday program to increase community socialization skills and plans for an intensive intervention team to facilitate in-home placements for those displaced from programs.

Judevine Center for Autistic Children
P. O. Box 28943
St. Louis, Missouri 63132
(314) 849-4440
Director: Lois Blackwell

Number served: 2?
Age range served: 4 - 17 years
Location: South St. Louis

The Judevine Center's philosophy is "to reach a child". The programs at Judevine are designed to break down a child's resistance to learning and interaction with others. There are 3 components of the Judevine program: 1.) the Service center that houses the educational classrooms for the children and also offers evaluation and assessment services, public education, crisis intervention and consulting services; 2.) the Training center which offers monthly 3-week training programs to parents and professionals; and 3.) the Research center which provides a laboratory for testing materials and operates experimental programs.

Suggested reading: O'Dell, S. L., Blackwell, L. J., Larcen, S. W., & Hogan, J. L. Competency-based training for severely behaviorally handicapped children and their parents. Journal of Autism and Childhood Schizophrenia, 1977, 7 (3), 231-242. The treatment program and accompanying parent training program at the Judevine Center for Autistic Children in described. A two-part assessment procedure is used which combines observation

with parent interviews. Training procedures and data collection techniques are described as well as the five major underlying trends of the program.

League School
567 Kingston Avenue
Brooklyn, New York 11203
(212) 498-2500
Director: Hannah Achtenberg

Number Served: 100
Age range served: 3 - 18 years
Location: Central Brooklyn

The League School offers individualized educational training for its students in 12 classrooms. This state supported program utilizes a psychoeducational approach in classrooms having a ratio of 2-5 to 1 student, depending on the students' functioning level and needs. Pre-vocational and vocational services are offered.

South Carolina Department of Mental Health Programs for Children and Adolescents with Autism
South Carolina Department of Mental Health
Division of Community Mental Health Services
Suite 314
P. O. Box 485
Columbia, South Carolina 29202
(803) 758-7385
Ms. Joann Tompkins, State Coordinator of Programs for Autistic Children and Adolescents

Number served: 130
Age range served: 1 - 26 years
Location: 8 programs located across the state

The South Carolina programs for autistic children and adolescents have adopted the Judevine Center as their programmatic model to insure quality control and consistency among all of the programs. The goals of the service system include providing adequate and appropriate services to the autistic population in South Carolina, training professionals and parents involved in the programs, public education regarding autism, and the provision of technical consultant services. The statewide service system currently provides services for adolescents at five sites, and serves the population in both residential and day programs at various types of facilities.

VIRGINIA SERVICE DIRECTORY

Public School Day Programs

The following school systems have classes specifically designed for autistic persons in the public schools:

Fairfax County Schools
Franklin County Schools
Richmond City Schools
Southeastern Cooperative Educational Program (SECEP) (serving Chesapeake, Franklin, Isle of Wight, Southampton, Norfolk, Portsmouth, Suffolk, and Virginia Beach)
Stafford County Regional Program

Other Day Programs

School for Contemporary Education, Springfield, Virginia

Residential Programs

DeJarnette Center for Human Development, Staunton, Virginia
Eastern State Hospital, Williamsburg, Virginia
Grafton School, Berryville, Virginia
Western State Hospital, Staunton, Virginia

THE VIRGINIA SOCIETY FOR AUTISTIC CHILDREN

President: William Lewis
14608 Tranor Avenue
Chester, Virginia 23831
(804) 541-1755 (home)
(804) 458-8506 (work)

Chapters

Central Virginia Chapter
President: Kathleen Lewis
14608 Tranor Avenue
Chester, Virginia 23831
(804) 541-1755

Northern Virginia Chapter
President: Marge DeBlaay
7804 Inverton Road #101
Annandale, Virginia 22003
(703) 941-8508

Shenandoah Valley Chapter
President: Mr. Edward Tubbs
Route 2, Box 607
Amisville, Virginia 22002
(703) 347-2721

Southwest Virginia Chapter
President: Geneva Hale
614 Harrison Avenue N. W.
Roanoke, Virginia 24016
(703) 343-3384

Tidewater Virginia Chapter
President: Leslie Arnold
301 Dover Court
Virginia Beach, Virginia 23454
(804) 428-8241

SOURCES OF INFORMATION ABOUT AUTISM

Journals

American Journal of Orthopsychiatry. Albany, New York: American Orthopsychiatric Association.

Archives of General Psychiatry. Chicago: American Medical Association.

Child Development. Chicago: University of Chicago Press.

Exceptional Children. Reston, Virginia: Council for Exceptional Children.

Journal of Abnormal Child Psychology. New York: Plenum Press.

Journal of Autism and Developmental Disorders. New York: Plenum Press. Formerly titled before 1979: Journal of Autism and Childhood Schizophrenia. 227 W. 17th Street, New York, NY 10011

Journal of Child Psychology and Psychiatry. Elmsford, New York: Pergamon Press.

TASH Review. Seattle, Washington: The Association of Severely Handicapped. Formerly titled before 1980: AAESPH Review.

Other Sources of Information

A Reader's Guide for Parents of Children with Mental, Physical or Emotional Disabilities. U. S. Department of Health, Education and Welfare. Public Health, 1979.

Advocate. Newsletter of National Society for Autistic Children. 1234 Massachusetts Ave. N.W., Washington, D. C. 20005

Balow, B. and Reid, G. Autism Sourcebook for Parents and Professionals. Minneapolis, Minnesota: University of Minnesota Special Education Programs, 1978.

Facts About Autism. U. S. Department of Health, Education and Welfare. Rockville, Md.: National Institute of Mental Health, 5600 Fishers Lane, 20852

How They Grow: A Handbook for Parents of Young Children with Autism. The National Society for Autistic Children, 1980.

Readings in Autism. Guilford, Connecticut: Special Learning Corporation, 1978.

The National Society for Autistic Children. Information and Referral Service, Suite 1017, 1234 Massachusetts Ave., N.W., Washington, D. C. 20005

NSAC Communicator. By and for those teaching children with autism. Available from NSAC, 227 West 17th Street, New York, N. Y. 10011

Proceedings. From each Annual Meeting and Conference of the National Society for Autistic Children. Available from the NSAC Bookstore.

APPENDIX D

AUTISM CHECKLIST

Autism is a life-long developmental disability which is found throughout the world in all types of families. The symptoms are caused by physical disorders of the brain and can occur by themself or in combination with other disorders such as retardation, blindness or deafness, epilepsy, etc. Because symptoms can change over time, please check those which occured in the child's development as well as those now present.

1. Social and language problems were present before child was 30 months of age. ☐

2. Problems affecting language and communication: ☐
   a. Mute, no speech ☐
   b. Uses words without attaching meaning to them. ☐
   c. Echos or repeats what is said by others. ☐
   d. Failure to use speech for social communication. ☐
   e. Problems with understanding communication from others. ☐
   f. Limited understanding of abstract terms or concepts. ☐
   g. Poor control of vocal pitch, volume and intonation. ☐
   h. Lack of appropriate gestures (disassociation of gestures from language). ☐
   i. Repetitive, stereotyped, inflexible use of words and phases. ☐
   j. Prolonged confusion over the use of pronouns. ☐
   k. Immature rhythms of speech. ☐
   l. Uses jargon or television talk. ☐

3. Disturbed developmental rates and sequences. ☐
   a. Normal coordination of the three developmental pathways (motor, social, adaptive) disrupted. Has uneven development across skill areas. ☐
   b. Gross motor development normal while fine motor development is delayed ☐

c. Motor development normal while social adaptive and cognitive development is delayed. ☐
d. Some cognitive skills developed at expected times while others were delayed or absent. ☐
e. Toileting and self-help skills not learned at appropriate level through motor skills appeared normal. ☐
f. Some skills appeared at expected times during development and then disappeared. ☐
g. Development in some non-language skill areas at normal or superior levels of development (music, math, mechanical abilities, puzzling skills) while language skills remain far below expected levels. ☐

4. Unusual or abnormal responses to sensory stimuli. ☐

a. Auditory symptoms: seems not to hear some sounds or some sounds may seem painful (through hearing assessed as normal). ☐
b. Does not react to pain or cold as expected ☐
c. Has unusual responses to smell, taste, or texture. ☐
d. Has odd sense of balance/may hold body in an unusual way; may whirl without getting dizzy. ☐
e. Has frequent repetitive movements, such as hand shaking and spinning. ☐
f. Visual symptoms: may appear to notice visual details rather than whole object or picture, may be fascinated with one visual stimuli such as lights. ☐
g. Smells or mouths things in the environment at an abnormally high rate. ☐
h. Has an abnormal response to being touched. ☐

5. Abnormal ways of relating to people, objects, and events. ☐

a. Abnormalities of social development. ☐
   1) Isolates self from others. ☐
   2) Disinterested in people ☐
   3) Apathetic and unresponsive; shows no desire to be held or cuddled. ☐
   4) Poor eye contact, looks "through" people. ☐
   5) Does not pick up social cues of others. ☐
   6) Fails to develop persistent relationships. ☐
   7) Does not reciprocate in social interactions or social conversation. ☐
   8) Does not initiate interaction with others. ☐

b. Ritualistic Behaviors
   1) Preoccupation with sameness. ☐
   2) Has rituals regarding schedules or objects in the environment. ☐
   3) Resists change. ☐

c. Play ☐
   1) Has no imaginative play. ☐
   2) Objects and toys used in unusual ways. ☐

NATIONAL SOCIETY FOR AUTISTIC CHILDREN

DEFINITION OF THE SYNDROME OF AUTISM

I. Essential features: Autism is a behaviorally defined syndrome. The essential features are typically manifested prior to 30 months of age and include disturbances of : (1) developmental rates and/or sequences, (2) responses to sensory stimuli, (3) speech, language, and cognitive capacities, and (4) capacities to relate to people, events, and objectives.

(1) Disturbances of developmental rates and sequences: Normal coordination of the three developmental pathways (motor, social-adaptive, cognitive) is disrupted. Delays, arrests, and/or regressions occur among or within one or more of the pathways.
   (a) within the motor pathway: for example, gross motor milestones may be normal while fine motor milestones are delayed;
   (b) between pathways: for example, motor milestones may be normal while social-adaptive and cognitive are delayed;
   (c) arrests, delays and regression: for example, motor development may be normal until age two when walking stops; some cognitive skills may develop at expected times while others are delayed or absent; imitative behavior and/or speech may be delayed in onset until age three, followed by rapid acquisition to expected developmental level.

(2) Disturbances of responses to sensory stimuli: There may be generalized hyper-reactivity or hypo-reactivity, and alteration of these two states over periods ranging from hours to months: for example,
   (a) visual symptoms: There may be close scrutiny of visual details, apparent non-use of eye contact, staring, prolonged regarding of hands or objects, attention to changing levels of illumination:
   (b) auditory symptoms: These may be close attention to self-induced sounds, non-response or over-response to varying levels of sound;
   (c) tactile symptoms: These may be over- or under- response to touch, pain, and temperatures, prolonged rubbing of surfaces, and sensitivity to food textures;
   (d) vestibular symptoms: These may be over- or under-reactions to gravity stimuli, whirling without dizziness, and preoccupation with spinning objects;
   (e) olfactory and gustatory symptoms: These may be repetitive sniffing, specific food preferences; and licking of inedible objects;
   (f) proprioceptive symptoms: These may be posturing,

darting-lunging movements, hand flapping, gesticulations and grimaces.

(3) Disturbances of speech, language-cognition, and non-verbal communication: Symptoms may include:
   (a) speech: for example, mutism, delayed onset, immature syntax and articulation, modulated but immature inflections;
   (b) language-cognition: for example, absent or limited symbolic capacity, specific cognitive capacities such as rote memory and visual-spatial relations intact with failure to develop the use of abstract terms, concepts, and reasoning; immediate delayed, negative echolalia with or without communicative intent; non-logical use of concepts; neologisms;
   (c) non-verbal communication: for example, absence or delayed development of appropriate gestures, dissociation of gestures from language, and failure to assign symbolic meaning to gestures.

(4) Disturbances of the capacity to appropriately relate to people, events, and objects, manifested by failure to develop appropriate responsibility to people and assignment of appropriate symbolic meaning to objects. For example,
   (a) People: absence, arrests and/or delays of smiling response, stranger anxiety, anticipatory responses to gestures, playing "peek-a-boo", playing "patty-cake", and waving "bye-bye", reciprocal use of eye contact and facial responsitivity, and appropriate reciprocal responsiveness to physical contact; failure to develop a relationship with significant caretakers or excessive reliance on caretakers. For example, caretakers may be treated indifferently interchangeably, with only mechanical clinging, or with panic or separation. Cooperative play and friendships (usually appearing between two and four) may not develop. Expected responses to adults and peers (usually appearing between five and seven) may develop, but are superficial, immature, and only in response to strong social cues.
   (b) Objectives: absent, arrested and/or delayed capacities to utilize objects and/or toys in an age-appropriate manner and/or to assign them symbolic and/or thematic meaning. Objects are often used in idiosyncratic, stereotypic and/or perserverative ways. Interference with this use of objects often results in expressions of discomfort and/or panic.

II. Associated features: Associated clinical features vary with age and include other disturbances of thought, mood, and behavior. Mood may be labile; crying may be unexplained or inconsolable; there may be giggling or laughing without identifiable stimuli. Delusions and hallucinatory experiences have been reported. There may be a lack of appreciation of real dangers, such as moving vehicles and heights as well as inappropriate fears. Self-injurious behaviors, such as hair pulling and hitting or biting parts of the body, may be present,

and stereotypic and repetitive movements of limbs or the entire body are common.

Current research estimates are that approximately 60 percent of autistic children have measured IQs below 50; 20 percent between 50-70, and 20 percent of 70 or more. The majority show extreme variability of intellectual functioning on formal IQ testing. They perform poorest on tasks requiring abstract thought, symbolism or sequential logic, and best on those assessing manipulative or visual-spatial skills and rote memory.

Recent studies indicate that the incidence of EEG abnormalities increases with age as does the possible onset of seizures.

III. Impairment: The syndrome is severely incapacitating. Periodic medical, neurological, psychological, educational, and behavioral reassessments are necessary. One must monitor the course of the syndrome to keep treatment planning apace with physiological and behavioral changes. Special educational facilities are almost always required. Behaviorally structured, functional, individualized programs have been demonstrated to be most helpful. Counseling families regarding total living planning is often desirable. Individual supportive psychotherapy and symptomatically targeted pharmacologic therapy may enhance social-adaptive functioning in selected persons. The severe form of the syndrome may include the most extreme forms of self-injurious, repetitive, highly unusual and aggressive behaviors. Such behaviors may be persistent and highly resistant to change, often requiring unique management, treatment, or teaching strategies.

IV. Age of onset: The exact age of onset in unknown, but symptoms have been reported and observed during the first months of life. Families may be unaware of early symptoms until the child fails to pass major developmental milestones (i.e., onset of walking, speech, socialization with peers). They may then date the onset of the syndrome to these missed milestones, whereas careful history taking may reveal that subtle symptoms were present earlier.

V. Etiology: The symptoms are best explained as expressive of a physical dysfunction within the central nervous system (CNS)--the exact nature and type of which has yet to be determined. This physical dysfunction of the CNS occurs independently or in association with other disorders which directly affect the central nervous system (i.e., maternal rubella, PKU, Down's Syndrome, epilepsy). In such cases, the diagnosis of Autism is made on Axis One, and the coexisting organic condition coded on Axis Three.

VI. Incidence and Sex Ratio: The syndrome has been identified in all parts of the world. It is very rare, with an incidence of approximately four or five per 10,000 births. It is found four to five times more commonly in males.

VII. Complications: Major complications are self-induced physical injuries, infections related to improper hygiene, dental problems related to persistent bruxism, and physical injuries due to inadvertent exposures.

VIII. Differential diagnosis:

(1) Mental retardation, etiology unkown and known: Here, developmental delays usually occur in all areas, and developmental sequences (motor, social, and cognitive) remain coordinated. Responses to sensory inputs, people and objects, and speech and language development are appropriate to the overall developmental level of cognitive functioning.

(2) Specific sensory deficits (e.g., deafness, blindness): Here compensatory behaviors may be confused with symptoms indicative of autism (e.g., hyper-reactivity to auditory, proprioceptive and tactile stimuli in blind children (i.e., blindness); hyper-responsivity to visual, proprioceptive (i.e., head shaking), and tactile stimuli in deaf children. When auditory and visual deficits are accompanied by mental retardation, speech, language, and the ability to relate to people and objects are appropriate to the overall developmental level of cognitive functioning.

(3) Congenital, developmental, and acquired disorders of central processing of language (aphasias): Here disturbances in language development and central processing are not accompanied by disturbances of responses to sensory inputs, dissociation of other developmental courses (motor, social), relatedness to people and objects. Aphasics may imitate and use gestures and other means to communicate symbolic content. If these disorders are accompanied by mental retardation then it must be assessed independently of the disturbances of central processing of language.

(4) Sequelae of physical or psychological trauma (e.g., syndromes previously described as hospitalism, maternal deprivation, anaclitic depression, sequelae of a chronically traumatizing environment): Here syndromes include failure to thrive infantile apathy and withdrawal, physical illnesses secondary to malnutrition or toxin ingestions and physical abuse, specific psychological fixations (psychogenic psychoses, severe neuroses, pathological character development), and all degrees of mental retardation. The pattern of symptoms and developmental delays are specific to the syndrome described, are related to specific etiologic factors in psychological and social environments, and respond to specific therapies if instituted before permanent changes have resulted.

(5) Schizophrenia, childhood type: Here, the disorder is characterized by the presence of a thought disorder (see definition in DSM III) (American Psychiatric Association, Note 1). Certain persons with the syndrome of autism as defined in DSM category 299.00 also may fit the criteria for childhood schizophrenia, particularly

at a later age (ages 5-12). In this case, both diagnoses should be listed so that subsequent researchers can objectively test the two main hypotheses regarding the relationship between these two syndromes, i.e., that autism is the earliest form of schizophrenia as manifested in late childhood or early adulthood or that autism and schizophrenia are distinct syndromes with different etiologies, family histories, and courses.

(6) Degenerative organic brain syndromes (e.g., Schilder's Disease, Heller's Syndrome) with or without mental retardation: Here the clinical course is characterized by progressive regressions in all or some areas of development (motor, social-adaptive, and cognitive). In the early stages, these regressions may mimic symptoms indicative of autism but are distinguishable by their relatively specific times of onset; characteristic signs and symptoms on neurological, psychological, and cognitive testing; and unremitting deteriorating course.

IX. Predisposing factors: None known.

X. Family factors: None known. The syndrome has been identified in all parts of the world. Recent studies have revealed no correlation between autism and parental psychopathology.

XI. Operational criteria: A, B, C, D, and E are required.

A. Signs and symptoms present prior to 30 months of age.

B. Disturbances of developmental rate and/or sequences.

C. Disturbances of responsiveness to sensory stimuli.

D. Disturbances of speech, language and cognitive capacities.

E. Disturbances of relating to people, events, and objects.

DSM-III

DEFINITION OF AUTISM

Infantile Autism. The essential features are a lack of responsiveness to other people (autism), gross impairment in communicative skills, and bizarre responses to various aspects of the environment, all developing within the first 30 months of age. Infantile Autism may be associated with known organic conditions, such as maternal rubella or phenylketonuria. In such cases the behavioral syndrome Infantile Autism should be recorded on Axis I, and the physical disorder, on Axis III.

The relationship of this category to Schizophrenia is controversial. Some believe that Infantile Autism is the earliest form of schizophrenia, whereas others believe that they are two distinct conditions. However, there is apparently no increased incidence of Schizophrenia in the families of children with Infantile Autism, which supports the hypothesis that the two disorders are unrelated.

The failure to develop interpersonal relationships is characterized by a lack of responsiveness to and a lack of interest in people, with a concomitant failure to develop normal attachment behavior. In infancy these deficiencies may be manifested by a failure to cuddle, by lack of eye contact and facial responsiveness, and by indifference or aversion to affection and physical contact. As a result, parents often suspect that the child is deaf. Adults may be treated as interchangeable, or the child may cling mechanically to a specific individual.

In early childhood there is invariably failure to develop cooperative play and friendships; but, as the children grow older, greater awareness of and attachment to parents and other familiar adults often develop. Some of the least handicapped may eventually reach a stage where they can become passively involved in other children's games or physical play such as running with other children. This apparent sociability is superficial, however, and can be a source of diagnostic confusion if mistaken for social relatedness when the diagnosis is made retrospectively.

Impairment in communication includes both verbal and nonverbal skills. Language may be totally absent. When it develops, it is often characterized by: immature grammatical structure, delayed or immediate echolalia, pronominal reversals (use of the pronoun "you" when "I" is the intended meaning), nominal aphasia (inability to name objects), inability to use abstract terms, metaphorical language (utterances whose usage is idiosyncratic and whose meaning is not clear), and abnormal speech melody, such as questionlike rises at ends of statements. Appropriate nonverbal communication, such as socially appropriate facial expressions and gestures, is often lacking.

Bizarre responses to the environment may take several forms. There may be resistance and even catastrophic reactions to minor changes in the environment, e.g., the child may scream when his or her place at the dinner table is changed. There is often attachment to odd objects, e.g., the child insists

on always carrying a string or rubber band. Ritualistic behavior may involve motor acts, such as hand clapping or repetitive peculiar hand movements, or insisting that fixed sequences of events precede going to bed. The fascination with movement may be exemplified by staring at fans, and the child may display inordinate interest in spinning objects. Music of all kinds may hold a special interest for the child. The child may be extremely interested in buttons, parts of the body, playing with water, or peculiar rote topics such as train schedules or historical dates. Tasks involving long-term memory, for example, recall of the exact words of songs heard years before, may be performed remarkably well.

Associated features. Mood may be labile; crying may be unexplained or inconsolable; there may be giggling or laughing without identifiable cause. There is often underresponsiveness or overresponsiveness to sensory stimuli, such as light, pain, or sound. Real dangers, such as moving vehicles and heights, may not be appreciated. Peculiar nervous habits, such as hair pulling or biting parts of the body, are sometimes present. Rocking or other rhythmic body movements also occur.

About 40% of children with the disorder have an IQ below 50; only 30% have an IQ of 70 or more. These children show extreme variability in intellectual functioning; they are often untestable on verbal tasks, and when testable, performance is worst on tasks demanding symbolic or abstract thought and sequential logic. However, tasks requiring manipulative or visual-spatial skills or immediate memory may be performed well.

Age of onset. By definition, the age at onset is always before 30 months. However, it may be difficult to establish age at onset retrospectively unless those who cared for the child during the early years are able to give accurate information about language development, sociability, and play. Parents of only children may be unaware of the problems until the child is observed with other children. The parents may then date the age at onset from that point, although a careful history will usually reveal that the abnormalities were present earlier.

Course. The disorder is chronic. Some of these children eventually are able to lead independent lives, with only minimal signs of the essential features of the disorder; but often the social awkwardness and ineptness persist (Residual State). Overall, one child in six makes an adequate social adjustment and is able to do some kind of regular work by adulthood; another one in six makes only a fair adjustment; and two-thirds remain severely handicapped and unable to lead independent lives. Factors related to long-term prognosis include IQ and development of language skills.

Impairment. The disorder is extremely incapacitating, and special educational facilities are almost always necessary.

Complications. The major complication is the development of epileptic seizures secondary to an underlying physical disorder; about 25% or more of cases develop seizures in adolescence or early adult life. Most of the children with an IQ below 50 develop seizures, but only very few of those with normal intelligence do so.

Prevalence. The disorder is very rare (2-4 cases per 10,000). It is apparently more common in the upper socioeconomic classes, but the reason for this is not clear.

Sex ratio. The disorder is about three times more common in boys than in girls.

Predisposing factors. Maternal rubella (especially when associated with infantile deafness or blindness), phenylketonuria, encephalitis, meningitis, and tuberous sclerosis are among the predisposing factors. In the past, certain familial interpersonal factors were thought to predispose to the development of this syndrome, but recent studies do not support this view.

Familial pattern. The prevalence of Infantile Autism is 50 times as great in siblings of children with the disorder than in the general population.

Differential diagnosis. In Mental Retardation there are often behavioral abnormalities similar to those seen in Infantile Autism. However, the full syndrome of Infantile Autism is rarely present. When both disorders are present, both diagnoses should be made. In Schizophrenia occurring in childhood there are oddities of behavior; but typically there are hallucinations, delusions, and loosening of associations or incoherence, which are not present in Infantile Autism. In Childhood Onset Pervasive Developmental Disorder, the age at onset is later than in Infantile Autism and the full syndrome of Infantile Autism is not present. In children with hearing impairments there will be a history of responding consistently only to very loud sounds, whereas in Infantile Autism the response to sounds is inconsistent. An audiogram can rule out the possiblity of hearing impairment. In Developmental Language Disorder, Receptive Type, the children generally make eye contact and will often try to communicate appropriately by means of gestures, whereas in Infantile Autism there is a pervasive lack of responsiveness.

Diagnostic criteria for Infantile Autism

A. Onset before 30 months of age.

B. Pervasive lack of responsiveness to other people (autism).

C. Gross deficits in language development.

D. If speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronomical reversal.

E. Bizarre responses to various aspects of the environment, e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects.

F. Absence of delusions, hallucinations, loosening of associations, and incoherence as in Schizophrenia.

Infantile Autism, Full Syndrome Present. Currently meets the criteria for Infantile Autism.

Infantile Autism, Residual State.

Diagnostic criteria for Infantile Autism, Residual State

A. Once had an illness that met the criteria for Infantile Autism.

B. The current clinical picture no longer meets the full criteria for Infantile Autism, but signs of the illness have persisted to the present, such as oddities of communication and social awkwardness.

SHORT DEFINITION OF AUTISM

Autism is a life-long developmental disability which typically appears during the first three years of life. The symptoms are caused by physical disorders of the brain and can occur by themselves or in combination with other disorders such as retardation, blindness, deafness, epilepsy, etc.

Characteristics of individuals with autism include:

1. Problems affecting language: lack of speech, echolalic speech, delayed speech, poor comprehension, or failure to use speech for social communication.

2. Uneven development in many areas: including such things as social skills, fine motor skills or self-help skills, and sometimes with normal or superior memory skills or skills in non-language areas.

3. Unusual reactions to sensory experiences. The sense of pain, balance, smell, touch or taste might be affected. May appear not to see or hear persons or objects in the environment.

4. Abnormal ways of relating to people, objects, and events. Apparent social aloofness and indifference. Lack of appropriate peer interactions or friendships.

5. Preoccupation with sameness, ritualistic behavior, resistance to change, objects and toys used in unusual way.

APPENDIX E

Grafton SCE

PARENT SURVEY

Parent/Guardian Name_____ Phone_____

Address_____ City or County_____

Person With Suspected Autism

Name_____

Date of Birth_____ Age_____ Sex_____

Race_____ Social Security No._____

Residence_____

What do you consider his/her level of functioning in the following areas? Please use the following definitions of Low, Medium, & High for questions 1 - 4. Check one box for each.

1. INTELLIGENCE: Cognitive functioning as determined by a standardized intelligence test or as otherwise estimated. If the individual is considered untestable, or results of standardized tests are otherwise unreliable, please use your own judgement in responding.
   - LO IQ below 50
   - MED IQ 50 -69
   - HI IQ 70 or over
2. SELF CARE: Personal self help functions as determined through observations or assessment tools.
   - LO Unable to feed, dress or toilet self without assistance.
   - MED Partially able to feed, dress, toilet self. .
   - HI Able to feed, dress, toilet self.
3. SOCIAL: Interpersonal and play functions as determined through observations or assessment tools.
   - LO Uses toys/materials inappropriately; engages in solitary activities.
   - MED Uses some toys/materials appropriately; has a friend or engages in activities with one or more age-mates.
   - HI Uses most toys/materials appropriately; approaches age-mates readily and pursues group activities.
4. BEHAVIOR: Personal behaviors as determined through observations or assessment tools.
   - LO Preponderance of severe self-destructiveness, destruction of property or others; staring; stereotypic movements; unusual reactions to some sensations.
   - MED Intermittant or mildly bizarre or destructive behaviors.
   - HI Absence of bizarre or destructive behaviors.
5. COMMUNICATION: Speech, language and non-verbal communication as defined by:
   - LO Mute; may be echolalic; lack of communicative intent.
   - MED Able to communicate basic needs, wishes through verbal or gestural language.
   - HI Has conversational speech.

1. Intelligence: ☐ Lo: IQ below 50 ☐ Med: IQ 50-69 ☐ Hi: IQ 75 or above
2. Self Care: ☐ Lo ☐ Med. ☐ Hi
3. Social: ☐ Lo ☐ Med. ☐ Hi
4. Behavior: ☐ Lo ☐ Med. ☐ Hi
5. Communication: ☐ Lo ☐ Med. ☐ Hi

Do you have any other handicapped persons in the family? ☐ Yes ☐ No

If yes, how many?_____

Describe handicap:_____

_____

We are interested in finding out how you first suspected that your child had a handicapping condition.

Who first suspected that your child had a handicapping condition?

- ☐ Self
- ☐ Community screening
- ☐ Pediatrician
- ☐ Other_____

What age was the child when you first suspected that he/she had a handicapping condition? _____years old.

What was the child's age at the time of his/her first diagnosis? _____years old.

What was the child's age when he/she first received services? _____years old.

We are interested in finding out what diagnostic services are offered to Virginia residents with autism. The following questions will help us to see what Virginia presently offers with regard to diagnostic services.

If your child has been diagnosed, what was the diagnosis? (check all that apply):

- ☐ Autistic
- ☐ Autistic-like
- ☐ Other_____

If yes, where was the diagnosis made?

Agency_____City_____County_____State____

At the time of the diagnosis, in what state were you residing?_____

How far did you have to travel to find diagnostic services?_____miles

Where is he/she presently placed?

Name of Facility_____

Address_____

Is the above facility a program designed and/or advertised for autistic individuals?

Yes ☐ No ☐ Don't know ☐

What type of program is the above:

☐ Residential Program ☐ Day Program

History of Services:

School/Facility	City, State	Age	Length of Stay From Mo./Yr.	to Mo./Yr.	Reason fo Leavin

Please check(✓) yes or no for each of the following:

We encourage you to make comments.

My child:

	Needs This Service		Receives This Service		I am Satisfied With This Service			Will Probab Need I Future
	Yes	No	Yes	No	Yes	No	Don't Know	Yes
I. Identification								
1. Diagnosis: Formal identification of autism								
2. Evaluation: Assessment for purposes of individual program planning								
Comments:								
II. Education, Training, or Treatment/Growth Services								
A. Language Development								
1. Language training								
2. Speech therapy								
3. Sign language								
4. Total communication system								
5. Other nonverbal language systems								
B. Socialization								
1. Play skills								
2. Peer interaction								
3. Interaction w/authority								
4. Group interaction								
5. Emotional expression								
6. Use of leisure time								
7. Use of community resources								
8. Money management								

My child:

	Needs This Service		Receives This Service		I am Satisfied With This Service			Will Probably Need in Future
	Yes	No	Yes	No	Yes	No	Don't Know	Yes
B. Socialization (Continued)								
9. Use of public transportation								
10. Sex education								
11. Planned experiences with non-handicapped individuals								
C. Personal Independent Skills								
1. Grooming								
2. Hygiene								
3. Housekeeping								
4. Care of personal items								
5. Independent living								
D. Preacademic Instruction (Readiness)								
E. Academic Instruction								
1. Reading								
2. Language Arts								
3. Math								
4. Social Studies								
5. Science								
6. Physical Education								
F. Specific Programming to Remediate Maladaptive Behaviors								
G. Prevocational Instruction								
H. Vocational Instruction								
I. Expressive Development								
1. Dance								
2. Music								
3. Art								

Comments:

Parent Survey (Continued)

	My child: Needs This Service		Receives This Service		I am Satisfied With This Service			Will Probably Need in Future	
	Yes	No	Yes	No	Yes	No	Don't Know	Yes	No
III. Related Support Services									
A. Transportation (Travel to & from services)									
B. Recreation (Activities for leisure time)									
C. Counseling - professional guidance of the individual for behavioral and emotional problems									
D. Psycho-therapy - treatment of the individual aimed at enhancing and changing intra-psychic or psychological functioning									
E. Psychiatric consultation-to program staff regarding individual served									
F. Psychological consultation-to program staff regarding individual served									
G. Physical or occupational therapy evaluating, improving, developing or restoring physical functions									
H. Speech pathology or language training - evaluation, consultation and individual remediation or development									
I. Social work - evaluation and mobilizing community resources, social case work with families									
J. Audiological - evaluation and consultation									
K. Health - medical									
L. Dental									
M. Music, dance, or art therapy									
N. Adaptive physical education									
O. Nutritional/dietary evaluation and counseling									

Comments:

My child:

	Needs This Service		Receives This Service		I am Satisfied With This Service			Will Probably Need In Future	
	Yes	No	Yes	No	Yes	No	Don't Know	Yes	No
IV. Family Services									
A. Communication - ongoing formal or informal communication									
B. Training - instruction to family in techniques for assisting individual with autism									
C. Counseling -guidance to family regarding the emotional impact of having an individual with autism									
D. Respite - temporary or emergency care									
E. Support									
1. Regular group meetings									
2. Parent - parent support									
F. Advocacy - informing families of their rights and of relevant organizations									
Comments:									
V. Employment Services									
A. Sheltered employment - work adjustment and job skill training									
B. Supervised/subsidized employment-support for employment of the chronically disabled in the natural environment									
C. Vocational rehabilitation - evaluation, training, and competitive job placement									
Comments:									

Parent Survey (Continued)

My child:

	Needs This Service		Receives This Service		I am Satisfied With This Service			Will Probably Need In Future	
	Yes	No	Yes	No	Yes	No	Don't Know	Yes	No
VI. Living Services									
A. Adult day care - supervised care with some training									
B. Child day care - supervised care with some training									
C. Transitional living arrangements									
D. Permanent special living arrangements - group home, apartment living, specialized foster care									
E. Residential services for children - 24 hour out of home care									
F. Residential services for adults - 24 hour out of home care									
G. Leisure Recreational resources									

Comments:

In order for us to provide a summary of the above information to the Developmental Disabilities Unit, we must have your signature indicating approval:

I give my permission for the information on this survey to be published in a report to the Developmental Disabilities Unit of the Department of Mental Health and Mental Retardation. I understand that this report may be distributed to other agencies and that this will be public information. However, I understand that the information will be reported as group data; therefore neither my name or the name of the reported person with autism, or any identifying information will be published.

Signature _____

Date _____

Relationship to person with suspected autism _____

APPENDIX F

A STATE-WIDE SERVICE PLAN FOR INDIVIDUALS WITH AUTISM

A project funded by the Virginia Developmental Disabilities Unit

- Conducted by -

Grafton School and School for Contemporary Education

DESCRIPTIVE SURVEY OF SERVICES
provided to
Individuals with Autism in Virginia

Preliminary Information for Local School Divisions

Public schools have a responsibility to provide special education services for all handicapped individuals between the ages of two and twenty-one years. "Autism" however is not recognized as a separate diagnostic category by the State Division of Special Education and Support Services for purposes of reimbursement or the establishment of separate program guidelines. Your division may be providing services to children with characteristics similiar to those listed in the enclosed definition of autism even though the children are not diagnosed as having autism. Please complete the following:

LOCAL DIVISION NAME: _____

ADDRESS: _____

_____

INDIVIDUAL COMPLETING THIS FORM - NAME _____

_____

POSITION _____ PHONE _____

FOR OUR LOCAL SCHOOL DIVISION:

	YES	NO
1. We are currently providing services to children formally diagnosed as having autism.	☐	☐
2. We are currently providing services to children with characteristics similiar to those listed on the enclosed definition of autism, but they are not labelled as having autism. If yes:	☐	☐

Typically such children are labelled as:

_____

_____

_____

3. Services to such children, whether or not they are specifically labelled as having autism, are provided directly by our division:		
a. In classes uniquely designed for individuals with autism.	☐	☐
b. In classes together with other identified populations. If yes:	☐	☐

Typically such classes are for:
(types of population) _____

_____

_____

4. Services to such children, whether or not they are specifically labelled as having autism, are secured elsewhere (Tuition, Contracting, etc.)	☐	☐

(name of facilities, location) _____

_____

_____

_____

5. Currently our division has /__/ has not /__/ identified such children.

6. Currently our division is /__/ is not /__/ serving such children.

7. a. Total number of all students enrolled in the division. _____

   b. Total number of students eligible for special education. _____

   c. Total number of students estimated with characteristics of autism. _____

   d. Total number of students specifically diagnosed with autism. _____

Thank you for your assistance. If your division is currently providing direct services to individuals with autism whether or not they are specifically so diagnosed, we will be sending you a survey form to describe these services.

Please return this form to:

The Autism Study
Grafton School
Box 469
Berryville, VA 22611

A STATE-WIDE SERVICE PLAN FOR INDIVIDUALS WITH AUTISM

A project funded by the Virginia Developmental Disabilities Unit

- Conducted by -

Grafton School and School for Contemporary Education

DESCRIPTIVE SURVEY OF SERVICES
provided to
Individuals with Autism in Virginia

NAME OF FACILITY_____

ADDRESS: _____

_____

CHIEF ADMINISTRATIVE OFFICER_____PHONE _____

INDIVIDUAL WITH PRIMARY RESPONSIBILITY FOR SERVICES TO INDIVIDUALS WITH AUTISM:

NAME_____PHONE_____

INDIVIDUAL COMPLETING THIS FORM:

NAME_____PHONE_____

POSITION_____DATE_____

TYPE OF AGENCY: (Check one)

_____ State operated by_____

_____ Local school division

_____ Public, other:_____

_____ Private, Non-profit

_____ Private, Profit

_____ Other:_____

Please complete this survey on the basis of individuals with characteristics similar to those listed on the enclosed definition of autism whether or not they are formally so diagnosed.

INSTRUCTIONS FOR QUESTION 1: The first question is the most complex question to answer. It does require that a judgement be made regarding each individual's level of functioning in each of five areas. It is suggested that the following steps might make it easiest to complete this form:

1. Collect the information on each individual child.

2. Complete a separate row for each individual as follows:

   a. IDENTIFICATION (Optional): This category is for your use only to assist you in assuring that each individual is counted once and only once. Identification may be initials, student number, number specifically assigned for this task, or any other designation you may wish. Individuals are <u>not</u> to be identified to the Autism Study on this form. The form is solely for the purpose of generating group summary information.

   b. AGE: Age in years as of last birth date.

   c. LEVEL OF FUNCTIONING: For each individual, check <u>one</u> level of functioning (LO, MED, HI), for <u>each</u> of the five areas. The following are definitions of each area of functioning with guidelines as to how to rate "LO", "MED", and "HI".

      1. <u>INTELLIGENCE</u>: Cognitive functioning as determined by a standardized intelligence test or as otherwise estimated. If the individual is considered untestable, or results of standardized tests are otherwise unreliable, please use your own judgement in responding.

         LO IQ below 50

         MED IQ 50 - 69

         HI IQ 70 or over

      2. <u>SELF CARE</u>: Personal self help functions as determined through observation or assessment tools.

         LO Unable to feed, dress or toilet self without assistance.

         MED Partially able to feed, dress, toilet self.

         HI Able to feed, dress, toilet self.

3. SOCIAL: Interpersonal and play functions as determined through observations or assessment tools.

   LO Uses toys/materials inappropriately; engages in solitary activities.

   MED Uses some toys/materials appropriately; has a friend or engages in activities with one or more age-mates.

   HI Uses most toys/materials appropriately; approaches age-mates readily and pursues group activities.

4. BEHAVIOR: Personal behaviors as determined through observations or assessment tools.

   LO Preponderance of severe self-destructiveness, destruction of property or others; staring; sterotypic movements; unusual reactions to some sensations.

   MED Intermittant or mildly bizarre or destructive behaviors.

   HI Absence of bizarre or destructive behaviors.

5. COMMUNICATION: Speech, language and non-verbal communication as defined by:

   LO Mute; may be echolalic; lack of communicative intent.

   MED Able to communicate basic needs, wishes through verbal or gestural language.

   HI Has conversational speech.

The following is an example of how the form might look:

			INTELLI-GENCE			SELF CARE			SOCIAL			BEHAVIOR			COMMUN-ICATION		
#	IDENTI-FICATION	AGE	LO	MED	HI	LO	MED	HI	LO	MED	HI	LO	MED	HI	LO	MED	HI
1	J.M.	7	X				X			X			X		X		
2	P.K.	7		X				X			X		X			X	
3.	J.N.	9		X			X		X					X	X		
4.	B.F.	12			X			X			X			X			X

A. DEMOGRAPHIC INFORMATION

1. Number of individuals with autism currently served by age and severity of impairment in five areas of functioning.

			LEVEL OF FUNCTIONING															
			INTELLI-GENCE			SELF CARE			SOCIAL			BEHAVIOR			COMMUN-ICATION			
#	IDENTI-FICATION	AGE	LO	MED	HI	LO	MED	HI	LO	MED	HI	LO	MED	HI	LO	MED	HI	
1																		
2																		
3																		
4																		
5																		
6																		
7																		
8																		
9																		
10																		
11																		
12																		
13																		
14																		
15																		
16																		
17																		
18																		
19																		
20																		
21																		
22																		
23																		
24																		

2. Using the same definitions of level of functioning, profile the individuals your facility could serve. Indicate "A" (Accept) or "E" (Exclude) for each type of individual.

   If there are different acceptance criteria for different age ranges, complete a separate row for each of these different age ranges. Otherwise, complete only row 1.

	AGES SERVED	LEVEL OF FUNCTIONING															
		INTELLI-GENCE			SELF CARE			SOCIAL			BEHAVIOR			COMMUN-ICATION		
	FROM - TO	LO	MED	HI	LO	MED	HI	LO	MED	HI	LO	MED	HI	LO	MED	HI
1	-															
2	-															
3	-															
4	-															

3. Program capacity with your present level of staffing and resources.

CAPACITY	
Ages From - To	Number
-	
-	
-	
-	
TOTAL	

4. Number of specifically identified individuals with characteristics of autism currently not receiving appropirate services (number on waiting list, waiting for placement, etc.). _____

5. Characteristics of the individuals not receiving appropriate services (see 4 above). Please complete the following insofar as you have the information using the same definition as for Question 1.

			LEVEL OF FUNCTIONING															
			INTELLI-GENCE			SELF CARE			SOCIAL			BEHAVIOR			COMMUN-ICATION		
#	IDENT-FICATION	AGE	LO	MED	HI	LO	MED	HI	LO	MED	HI	LO	MED	HI	LO	MED	HI
1																	
2																	
3																	
4																	
5																	
6																	
7																	
8																	
9																	
10																	

B. TYPE OF SERVICES PROVIDED - Check boxes for those services for which you provide direct services.

	Yes	No
1. Identification		
a. Child Find: Program actively seeks to find individuals with autism including public awareness activity, screening and referral.	☐	☐
b. Diagnosis: Formal identification of autism.	☐	☐
c. Evaluation: Assessment for purposes of individual program planning	☐	☐
d. Other: _____	☐	☐
2. Education, Training, or Treatment/Growth Services		
a. Language Development	☐	☐
1. Language training	☐	☐
2. Speech therapy	☐	☐
3. Sign language	☐	☐
4. Total communication system	☐	☐
5. Other nonverbal language systems	☐	☐
b. Socialization	☐	☐
1. Play skills	☐	☐
2. Peer interaction	☐	☐
3. Interaction w/authority	☐	☐
4. Group Interaction	☐	☐
5. Emotional expression	☐	☐
6. Use of leisure time	☐	☐
7. Use of community resources	☐	☐
8. Money management	☐	☐
9. Use of public transportation	☐	☐
10. Sex education	☐	☐
11. Planned experiences with non-handicapped individuals	☐	☐
c. Personal Independent Skills	☐	☐
1. Grooming	☐	☐
2. Hygiene	☐	☐
3. Housekeeping	☐	☐
4. Care of personal items	☐	☐
5. Independent living	☐	☐

			Yes	No
d.	Preacademics (readiness)		☐	☐
e.	Academic Instruction		☐	☐
	1. Reading	☐ ☐		
	2. Language Arts	☐ ☐		
	3. Math	☐ ☐		
	4. Social Studies	☐ ☐		
	5. Science	☐ ☐		
	6. Physical Education	☐ ☐		
f.	Specific Programming to Remediate Maladaptive Behaviors		☐	☐
g.	Prevocational Instruction		☐	☐
h.	Vocational Instruction		☐	☐
i.	Expressive Development		☐	☐
	1. Dance	☐ ☐		
	2. Music	☐ ☐		
	3. Art	☐ ☐		
j.	Others: _____		☐	☐
3.	Related Support Services			
a.	Transportation (Travel to and from services)		☐	☐
b.	Recreation (activities for leisure time)		☐	☐
c.	Counseling - professional guidance of the individual for behavioral and emotional problems		☐	☐
d.	Psychotherapy - treatment of the individual aimed at enhancing and changing intrapsychic or psychological functioning		☐	☐
e.	Psychiatric consultation - to program staff regarding individuals served		☐	☐
f.	Psychological consultation - to program staff regarding individuals served		☐	☐
g.	Physical or occupational therapy - evaluating, improving, developing or restoring physical functions		☐	☐

	Yes	No
h. Speech pathology or language training - evaluation, consultation and individual remediation or development	☐	☐
i. Social work - evaluation and mobilizing community resources, social case work with families	☐	☐
j. Audiological - evaluation and consultation	☐	☐
k. Health-medical	☐	☐
l. Dental	☐	☐
m. Music, dance, or art therapy	☐	☐
n. Adaptive physical education	☐	☐
o. Nutritional/dietary evaluation and counseling	☐	☐
p. Other:_____	☐	☐
4. Family Services		
a. Communication - ongoing formal or informal communication	☐	☐
b. Training - instruction to family in techniques for assisting individual with autism	☐	☐
c. Counseling - guidance to family regarding the emotional impact of having an individual with autism	☐	☐
d. Respite - temporary or emergency care	☐	☐
e. Support	Yes	No
1. Regular group meetings	☐	☐
2. Parent - parent support	☐	☐
f. Advocacy - informing families of their and of relevant organizations	☐	☐
g. Other:_____	☐	☐
5. Employment Services		
a. Sheltered employment - work adjustment and job skill training	☐	☐

	Yes	No
b. Supervised/subsidized employment support for employment of the chronically disabled in the natural environment	☐	☐
c. Vocational rehabilitation - evaluation, training, and competitive job placement	☐	☐
d. Other: _____	☐	☐
6. Living Services		
a. Adult day care - supervised care with some training	☐	☐
b. Child day care - supervised care with some training	☐	☐
c. Transitional living arrangements	☐	☐
d. Permanent special living arrangements - group home, apartment living, specialized foster care	☐	☐
e. Residential services for children - 24 hour out of home care	☐	☐
f. Residential services for adults - 24 hour out of home care	☐	☐
g. Leisure/Recreational resources	☐	☐
h. Other: _____	☐	☐
7. Social, Legal, Information Services		
a. Protective social/socio-legal - protection of rights and interests	☐	☐
b. Follow along - long term assistance for meeting needs, find services, etc.	☐	☐
c. Information - Referral - locating resources and services	☐	☐
d. Consultation & Training - assisting programs to better meet the needs of individuals with autism	☐	☐
e. Follow-up - active assistance in transition to other services upon termination of your program services	☐	☐
f. Other: _____	☐	☐

	Yes	No
8. Other (please list)		
a. _____	☐	☐
b. _____	☐	☐

C. SERVICES SECURED OUTSIDE THE FACILITY

While served by our facility, the following services are obtained for these individuals elsewhere:

	Type of Service	Name of Facility Providing Service
1.	_____	_____
2.	_____	_____
3.	_____	_____
4.	_____	_____
5.	_____	_____

D. PROGRAM CHARACTERISTICS

1. Length of time individual is in the program per day._____

2. Number of days per year services are offered._____

3. Length of time individuals stay in program:

   a. Shortest length of time an individual has been enrolled._____
   b. Longest length of time an individual has been enrolled. _____
   c. Average length of stay. _____
   d. Number of individuals who exited from your program last year. _____

4. Describe the degree and nature of contact individuals have with non-handicapped individuals.

_____

_____

_____

_____

_____

5. Describe the program philosophy or service (or attach if published).

_____

_____

_____

_____

_____

E. PERSONNEL

1. Number and Type of Staff Providing Services to Individuals with Autism.

Directions: It is recognized that many programs are structured such that staff have responsibilities that are related to a number of clients and not just clients with autism. Please complete the form as follows:

a. Job Title: Positions (such as Program Director, Teacher, Psychologist, etc.) of all staff related to services for clients with autism.

b. Number of Staff-FTE: Number of staff in each position, reported in terms of full time equivalence (FTE), even though all of that time is not spent in responsibilities exclusively for clients with autism. For example, if a program had three half-time psychologists, this column should read (1.5); three persons totaling 1½ full time positions.

c. Total Number of Individuals (autistic & not) Served by this Position. If for example, the three half-time psychologists served an entire program serving 100 children, then 100 should be written in column (c).

d. Total Number of Autistic Individuals Served by this Position. Continuing the above example, if out of 100 children, 12 were considered to have autism, 12 should be placed in column (d).

(a) JOB TITLE	(b) NUMBER OF STAFF-FTE	(c) TOTAL NO. INDIVIDUALS (AUTISTIC AND NOT) SERVED BY THIS POSITION	(d) TOTAL NO. OF AUTISTIC INDIVIDUALS SERVED BY THIS POSITION
Administrative			
Professional			
Support			

2. Staff Ratios: The ratio of direct service staff, at any one time, to individuals served for each major type of service offered.

Service	Ratio
_____	_____ : _____
_____	_____ : _____
_____	_____ : _____
_____	_____ : _____
_____	_____ : _____
_____	_____ : _____
_____	_____ : _____
_____	_____ : _____
_____	_____ : _____

F. COST OF SERVICES

1. Overall Cost of Services: (Budget Year _____ - _____)

a. FEES: If fees are established, please list the fee per individual unit of service that is charged.

Service Description	Definition of Serv. Desc.	Fee/Unit
1.		
2.		
3.		
4.		
5.		
6.		

b. COSTS: If fees are not charged, please list total costs per service unit.

Service Descritpion	Definition of Serv. Desc.	Cost
1.		
2.		
3.		
4.		
5.		
6.		

2. Income: Please list sources of income and estimate the percent of total cost of services for individuals with autism that is paid by each source.

	Source	Per Cent
1.	_____	_____
2.	_____	_____
3.	_____	_____
4.	_____	_____
5.	_____	_____

G. SERVICE NEEDS

1. Follow UP: When individuals terminate services with your facility, where do they go?

Name of Facility	Type of Service
_____	_____
_____	_____
_____	_____
_____	_____

Upon termination, what type of special services are most needed by individuals with autism?

_____

_____

_____

_____

_____

2. Program Development: Do you fee that your facility needs assistance in the following areas:

	Yes	No
a. Securing appropriately trained staff	☐	☐
b. Training current staff	☐	☐
c. Securing adequate funding	☐	☐
d. Program planning for:	Yes	No
1) Identification	☐	☐
2) Education, training or treatment	☐	☐
3) Related and support services	☐	☐
4) Family services	☐	☐
5) Employment services	☐	☐
6) Living services	☐	☐
7) Social, legal, information services	☐	☐
e. Securing appropriate curriculum materials	☐	☐
f. Other: _____	☐	☐
_____	☐	☐

APPENDIX G

THE VARIABLES ON THE EVALUATION FORM

Criteria for Evaluation of Services

Status:

"Not Applicable" - the service is not meant to be offered.
"No Service" - the service should be offered but it is not offered.
"Plan" - a written plan exists for the provision of the service.
"Partially Implemented" - a written plan exists for the provision of service and is partially implemented.
"Fully Implemented" - a written plan exists for the provision of service and is fully implemented.

Evaluation:

"Needs Improvement" - the plan for service and/or degree of implementation of service need improvement.
"Acceptable" - the plan for service and/or degree of implementation is currently acceptable.

Importance: (of services "needing improvement")

"Critical" - first priority for improvement.
"Important" - 2nd priority for improvement.
"Desirable" - 3rd priority for improvement.
Note: the above levels of importance are not to be confused with the Priority Quotient which is a combination of "status", "evaluation", and "importance" ratings.

Services Evaluated

A. General Facility Administration

1. Policy - Procedure
   - -Program has a statement of philosophy that includes:
     - -an outline of program objectives &
     - -the strategies used to attain the objectives
   - -Implementation is consistent with stated philosophy
   - -There are mechanisms for staff & consumer review & input into general operating policies and procedures
   - -Services are provided in the least restrictive environment appropriate to the needs of the clients

2. Personnel
   - -Personnel Qualifications
     - -Staff are qualified to provide the services
     - -There is a sufficient number of staff to serve the clients
     - -There are procedures for active recruitment of qualified staff
   - -Personnel Management
     - -All personnel have clear role descriptions
     - -There is regular feedback and support for supervisory personnel
     - -Staff have adequate time to plan and implement services

-Personnel Development
  -Program adequately orients new staff
  -Program has procedures for assessing staff development needs
  -Program uses variety of approaches for staff development
-Interpersonal relations
  -Staff are cohesive and mutually supportive
  -A positive attitude pervades the program
  -Clients are treated positively and with dignity

3. Coordination of Services
-Intake
  -Referral agencies have accurate understanding of program, clients and services
  -Referral agencies have accurate understanding of intake procedures
  -Intake procedures accurately select appropriate clients
  -Intake procedures are efficient
-Services
  -There are procedures to assure various services provided to an individual have similar & coordinated objectives
  -Strategies used by different services are similar or complimentary
  -There are procedures to assure ongoing sharing of client progress among services
  -Services are coordinated with services provided by other facilities to the client
-Exit
  -The appropriateness of exit from program is periodically questioned
  -Concrete follow-up plans are made prior to exit
  -Follow-up activity provides smooth transition to subsequent service

4. Community Integration
-Program has procedures for determining and addressing community needs
-Community is aware of services provided
-Community is supportive of program
-There are procedures for community citizen participation in the program
-Program staff is active in the professional community

5. Program Evaluation
-Program periodically evaluates its service effectiveness
-There are procedures for altering program services based on program evaluation

B. Individual Client Planning
1. Annual Plan for Individual Clients
-The program has used a variety of test instruments or procedures to determine appropriate annual goals
-Program solicitors input for ANNUAL PLAN from all appropriate sources
-The individualized ANNUAL PLANS lead toward goals that:
  -Are functional skills for the client
  -Lead toward the least restrictive environment
-The ANNUAL PLAN includes a plan for evaluation of progress toward the accomplishment of ANNUAL GOALS

2. Short Term Objectives
   -The program has written short-term objectives that
      -Are individualized
      -Are measurable
      -Are clearly delineated regarding the conditions under which the behaviors are to occur
      -Have clear criteria for mastery
      -Are sequenced developmentally in small enough increments so that success is likely
      -Are reviewed periodically
      -Are changed as a result of review
   -The program has used the community as a resource for programming
   -The program has involved parents/guardians and clients in the educational process
   -Provision has been made to generalize skills taught into other appropriate environments

C. Observation of Services
   1. Short Term Objectives
      -Direct care staff can be observed providing:
         -Feedback to clients/students
         -Data based programming
         -Implementation consistent with the written plan
         -Consistent programming/interventions across staff
         -Individualized programming

   2. Service Environment
      -The program has a functional service environment that is:
         -Adequate for the type of service provided
         -Divided into appropriate spaces
         -Accessible to handicapped individuals
         -Free from distractions as appropriate
      -The atmosphere of the service environment is:
         -Attractive
         -Clean
         -Comfortable
         -Free from clutter
         -As close as possible to a normal environment
      -Program has materials and equipment necessary to implement the stated objectives of individual clients/students
      -Implementation is consistent with stated philosophy
      -Services
         -There are procedures to assure various services provided to an individual have similar & coordinated objectives
         -Strategies used by different services are similar or complimentary
         -Services are coordinated with services provided by other facilities to the client
      -Interpersonal relations
         -Staff are cohesive and mutually supportive
         -A positive attitude pervades the program
         -Clients are treated positively and with dignity

-Services
-Children are appropriately diagnosed in the service
-Children are appropriately placed in the service
-When service needs are identified, service is provided within a reasonable time frame
-Exit
-The appropriateness of exit from the program is periodically questioned
-Concrete follow-up plans are made prior to exit
-Follow-up activity provides smooth transition to subsequent service

D. Identification

1. Child Find
-Program has specific procedures for Child Find
-System has identified person(s) responsible for Child Find
-System provides public with program information which includes:
-Indications of handicapping conditions
-Services available
-Benefits service
-General criteria for eligibility
-Referral procedures
-System makes information available to:
-Community at large
-Parents
-Agencies (public & private)
-Medical community
-The program uses specific strategies of Child Find for its hard to reach populations (e.g., rural, inner-city, children not receiving health care, etc.)
-Program has specific procedures for screening
-A Child Find record keeping system is maintained and used in program evaluation

2. Diagnosis
-The program uses a multi-disciplinary approach including but not limited to:
-Medical exam including neurological if indicated
-Visual examination
-Auditory screening
-Speech and language screening
-Social assessment
-Educational assessments as appropriate for the individual
-Psychological assessments as appropriate for the individual
-Developmental assessments as appropriate for the individual
-The program uses a variety of test instruments and procedures
-The diagnostic procedure includes a thorough parent interview procedure in effect
-The diagnostic team has written criteria for determining presence or absence of the syndrome

3. Evaluation
-Evaluation for provisions of service include assessment in:

-Physical development
-Sensorimotor development
-Social development
-Affective development
-Cognitive development

-The evaluation process:
-Identifies the functional strength and weaknesses of the individual
-Has a written schedule for re-assessment that meet applicable guidelines for the service

-The evaluation procedure utilizes:
-Multi-disciplinary approach
-Variety of test instruments
-Non-biased tests including non-verbal tests as indicated
-Parent input

-Results of evaluation are:
-Shared with the individual and family
-Interpreted to the individual as needed
-Written in terms that facilitate clear communication with other service agencies and the family

E. Education

1. Language Development

-The program provides
-Language training
-Speech therapy
-Sign language
-Total communication
-Other non-verbal communication systems

-The service is provided for a sufficient number of hours per week to meet the needs of students as stated in the annual plan

-The staff have access to materials and equipment necessary to implement the objectives

-The program provides for generalization of skills between service settings

-Speech and language consultation from professional to line staff is available on a regularly scheduled basis

2. Socialization

-The program provides education and training in:
-Play skills
-Peer interaction
-Interaction with authority
-Group interaction
-Emotional expression
-Sex education
-Planned experiences with non-handicapped individuals

3. Personal Independent Skills

-The program provided education and skills training in:
-Eating and drinking skills
-Toileting skills
-Personal hygiene
-Dressing skills

-Grooming skills
-Health care skills (first aid)
-Functional communication skills
-Home management skills
-Time management skills

-The environment for providing the above skills is as near as possible to the normal environment

-The program provides systematic procedures to ensure that the skills taught are generalized into appropriate settings in the community

-Use of leisure time

-Use of community resources

-Money management

-Use of public transportation

4. Pre-academic

-The program provides instruction in:

-Pre-reading
-Pre-math
-Pre-writing

5. Academic Instruction

-The program provides instruction in:

-Reading
-Language Arts
-Math
-Social Studies
-Science
-Physical Education

-Materials at the appropriate levels of complexity are available for instruction in each subject area listed in the IEP

6. Specific Programming to Remediate Maladaptive Behaviors

-The program has in effect a written policy for procedures to remediate maladaptive behaviors which:

-Is distributed to parent/guardians (and clients where applicable) and approved for use
-Is distributed and used by staff
-Prohibits physical and verbal abuse of any kind

-Written plans are available for each behavior intervention in effect which:

-Specify the behavioral objectives of the program
-Specify the schedule for use of the method
-Specify the person(s) responsible for carrying out the program
-Specify the person responsible for monitoring the program
-Specify the data that are to be collected in order to assess progress toward the objectives
-Specify future criteria which will result in changes of the written program

-If adverse consequences are in effect or behavior control drugs are used:

-There must be written evidence that positive procedures were systematically tried and were ineffective

-There is written permission from parent/guardian
-There is a clearly written policy/procedure for the use of aversives

7. Prevocational Instruction
-The program provides orientation to work and employment including:
-Job opportunities and availability
-Characteristics of work environments
-Job duties and benefits
-The program provides or procures training for the development of work adjustment skills including:
-Communication procedures
-Job mobility requirements
-Interpersonal work relationships
-Job seeking skills
-Job acceptable dress and hygiene
-Adaptation to changes in work or employment conditions and responsibilities

8. Vocational Instruction
-The vocational training plan provided by the program includes:
-Individual objectives
-Projected time frames for achieving the objectives
-Training methodologies, equipment and materials
-Procedures for evaluating and assessing the work training progr
-Vocational training activities as appropriate to the developmental levels and chronological ages of the individuals being served
-The program has written assessment data to determine the training procedures appropriate for the individual

9. Expressive Development
-The program activity encourages participation and skill training in:
-Dance
-Music
-Art
-When splinter skills in the above areas are evident, the facility procures services as needed to maximize development

F. Related Support Services
1. Transportation
-The program has in evidence
-Written description of service
-Written policy distributed to staff on emergency procedures
-Safeguards for clients including but not limited to:
-Adequate insurance
-Procedures for managing behavior on the vehicle
-The agency shall evidence vehicles which:
-Are properly inspected and equipped according to state/local regulations
-Do not embarrass or otherwise produce notoriety for individuals using service

2. Recreation
-The program utilizes community recreation resources to the maximum possible extent

-The program has a written, annually updated, plan for a range of indoor and outdoor activities to provide skill training and participation in the use of leisure time activities
-The program has mechanisms in place to keep the population it serves informed of various opportunities for recreation
-The program provides transportation as necessary to ensure that individuals in the program can participate in community recreation activities
-The program teaches leisure activities that have carry over value for the individual's future life
-The recreation activities provided cover a variety of physical and cultural experiences
-The ratio of staff to clients/students allows for skill training as well as participation in the activity

3. Counseling
-The program has a written referral procedure
-The counseling model is appropriate to the developmental needs of the individual/client
-Case notes are maintained which document interventions and results
-The counseling strategy includes procedures for integrating counseling goals with other aspects of the client's environment

4. Psychotherapy
-The program has a written referral procedure
-The therapeutic model is appropriate to the developmental needs of the client
-Case notes are maintained which document interventions and results
-The therapeutic strategy includes procedures for integrating therapy goals with other aspects of the client's environment

5. Physical or Occupational Therapy
-The program has:
  -Written criteria for entry into the service
  -Materials and equipment inventory appropriate to service goals
-The program provides for coordination between service areas
-The staff provides consultation or instruction as appropriate to other direct care staff & the individual's family

6. Speech Pathology/Language Training
-The program provides written criteria for entry into the service
-Day to day records are in evidence which describes student progress
-Evidence is available that daily progress records are used to make instructional decisions
-The program provides:
  -Language training
  -Speech therapy
  -Sign language
  -Total communication
  -Other non-verbal communication systems
-The service is provided for a sufficient number of hours per week to meet the needs of students as stated in the annual plan

-The staff have access to materials and equipment necessary to implement the objectives

7. Speech Pathology/Language Training (continued)
-The program provides for generalization of skills between service settings
-Speech and language consultation from professional to line staff is available on a regularly scheduled basis

8. Social Work
-The program provides the services necessary for:
  -Case management
  -Parent contact
  -Liasion between program/home
  -Follow along

9. Audiological
-The program provides or procures audiological examinations appropriate to the developmental/cognitive level of the client
  -Pure tone
  -Impedence
  -Brain stem evoked response
-The program has appropriate instruments or access to appropriate instruments
-Evaluation for hearing impaired children occurs annually

10. Health-Medical
-The program has
  -Medical records on file
  -Annual physical for each individual on file
  -A written plan for medication dispensal
  -Adequate first aid equipment readily available in places known to staff
  -Emergency procedures written and made known to staff
  -Procedures written and made known to staff regarding notification of parents/guardians of medical care required
  -Access to physicians and nurses on a 24 hour basis

11. Dental
-The service makes provision for dental specialties of:
  -Pedodontics
  -Orthodontics
  -Periodontics
  -Prosthodontics
  -Endodontics
  -Oral surgery
  -Oral medicine
-The service provides periodic oral prophylaxis by a dentist or dental hygienist for each individual
-Provision for daily oral care
-Instruction in oral hygiene methods

12. Music, Dance, Art Therapy
-The program has written criteria for entry into the service
-The program has a written service plan in evidence for each individual enrolled in the service area
-Daily records are in evidence which demonstrate progress toward the stated service goals

13. Adaptive Physical Education
-The program has written criteria for entry into the services
-The program has a written service plan in evidence for each individual enrolled in the service area
-Daily records are in evidence which demonstrate progress toward the stated service goals

14. Nutritional/dietary Evaluation
-The service provides for determination of dietary requirements and assessment of intake and adequacy through dietary interview, clinical evaluation and biological assessment
-The service provides for:
  -Assessment of food service practices
  -Evaluation of the total food intake of the individual
  -Assessment of feeding practices, capabilities and potential
-Other

G. Family Services

1. Communication
-Program informs parents of their due process rights and responsibilities
-Program offers parent/staff conferences
-Program involves parents in planning program activities
-Program actively involves parents in their children's educational activities
-Program has procedures for parent observation of the child's activities
-Program has system for collecting parent feedback about services to clients and families

2. Training
-The program provides home training services that:
  -Are consistent with the management & training program carried out within the educational training program
  -Offers the family instruction in planning and carrying out teaching or behavior management sequences
  -Offers continuing support and assistance
  -Offers instruction in the use of specialized instructional materials or techniques

3. Counseling
-The program provides on-going assessment of family needs related to their child's education
-The agency counsels with the family, when appropriate, concerning interpersonal conflicts or conflicts arising from difficulties created by the identified individual with autism

-Agency provides counseling for parents in times of crisis
-Group meetings are conducted for siblings or parents of identified individuals
-Materials and training are available to help parents understand and cope with the difficulties associated with autism

4. Respite
-The agency has a written plan for selecting, training and evaluating staff
-There are written procedures for:
  -Acquisition of the service
  -Length of stay
  -Extension of length of stay
-The agency provides for continuity of other services

5. Support
-The program has procedure in effect for:
  -Parent orientation
  -Regularly scheduled meetings to provide group or individual support services
-The program has information or knowledge regarding regional services to be able to refer families to services not available within the program
-The program informs parents of organizations and groups that relate to handicapped children and families
-The agency provides parent to parent activities for newly identified parents and in time of crisis

6. Advocacy
-The agency providing services is independent of any service providing direct care
-The agency's written policies and procedures include:
  -Identifying individuals who want or need the services
  -Matching individuals and advocate in a beneficial relationship
-When individuals are disabled or disadvantaged in such a way, or to such a degree, that they cannot satisfy their major needs or effectively represent their own interests in society, the program provides advocates, who, in important functions, act for them or with them, and who vigorously support, represent, and safeguard their needs

H. Employment Services
1. Sheltered Employment
-The program assists individuals to move as far as possible along the continuum toward paid employment and entry into the mainstream of society as an independent worker
-The program provides a program of orientation to work and employment
-The agency provides work evaluation and assessment activities to determine the training or employment programs appropriate for the individual
-Work training and employment provided or procured by the agency meet individual client needs as to variety and graduated complexity of learning experiences such as:

-Work activity centers
-Sheltered employment centers
-Home employment
-Work stations in industry
-Competitive employment
-Self-employment

-Work training includes:
-Work activities training that provides for development of the individual
-Training that develops skills specific to identified jobs
-Work adjustment training that develops appropriate attitudes and work habits
-On-the-job training that leads to placement in a specific job
-Activities that familiarize the individual with production requirements

2. Supervised/subsidized Employment
-Sheltered employment is in regular service areas and including and among non-handicapped workers
-The agency procures or provides job placement opportunities in a variety of settings:
-Work activity centers
-Sheltered employment centers
-Home centers
-Industry
-Competitive employment
-Self employment
-The agency/program provides or procures follow-along services to assure that the individual adjusts to the work setting

3. Vocational Rehabilitation
-Program provides education to community regarding needs and assets of handicapped in the community job markets
-Program demonstrates knowledge of employment practices and need of the community
-Program provides thorough evaluation of vocational strengths and weaknesses to plan for appropriate vocational rehabilitation
-Program provides clients with training appropriate to functioning levels
-Program provides clients job opportunities alongside non-handicapped individuals.
-Program provides follow along services for all clients currently being served or previously served
-Program provides employment opportunities appropriate to the training
-Program works in the community to develop jobs
-Program provides modifications in the job setting or equipment to meet needs of client being served
-Program meets clients needs in assuring that work environment is safe for the handicapped
-Other

I. Living Services

1. Adult Day Care
   - -The program has
     - -Goals leading to functional skills
     - -Goals leading to LRE
     - -Training in leisure time activities
     - -Training in social skills
     - -Training methods and materials that take into account levels of functioning, modality strengths & weaknesses, physical constraints

2. Child Day Care
   - -The program has:
     - -Goals leading to functional skills
     - -Goals leading to least restrictive environment
     - -Training in leisure time activities
     - -Training in social skills
     - -Training methods and materials that take into account levels of functioning, modality strenths & weaknesses, physical constraints

3. Transitional Living Arrangements
   - -The program encourages free access to community resources
   - -Training is in evidence that will help clients make the transition to a less restricted living arrangement
   - -The furnishings and equipment in individual rooms or group living areas are designed to facilitate training toward maximum self help
   - -Furnishings and equipment are "homelike" so that skills learned in the transitional space can be transferred or generalized into a less restrictive environment

4. Permanent Special Living Arrangements - Group Home, apartment living, specialized foster care
   - -The program is designed to provide living experiences appropriate to the function-level of the individual
   - -Support and supervision is provided at levels required by the individual being served
   - -The arrangement provides an environment that facilitates a continuity with culturally normative living patterns
   - -The living arrangement:
     - -Is located within the community
     - -Has interior and exterior features that are compatible to those of other residences in the neighborhood
     - -Are separate from the sites of educational or vocational training
   - -Staff supervising the special living arrangements have training to increase their ability to provide effective development enhancing services to autistic individuals
   - -Staff supervising the special living arrangements assure that individual living in the facility have access to needed resources and activities

5. Residential Children

-The program implements individualized instruction for each child in:
  -Carrying out daily routine independently
  -Replacing maladaptive behavior with appropriate behaviors that are incompatible
-Record keeping and reporting systems are in effect to measure each child's progress toward individualized goal
-The program has systems in effect for changing methods and procedures when children are not attaining goals as written
-There is a written policy in effect that requires evaluation of the appropriateness of the placement on at least an annual basis
-Ratios of staff to children are sufficient to carry out parental care functions:
  -Sharing structured and unstructured activity periods
  -Providing periods for responding on a 1:1 basis to child's expressions of feelings and thoughts
  -Caring for children's needs when well or sick
  -Providing high frequency positive feedback when children are responding appropriately to their environment
  -Carrying out planned interventions without neglecting other children in the program for inappropriate periods
  -Arranging and transporting children to appointments and other necessary destinations where having a familiar person might be important to the child or to the outcome of the appointment
-Individuals are fed at a leisurely rate, and the time allowed for eating is such as to permit adequate nutrition, promote the development of self-feeding abilities, encourage socialization, and provide a pleasant mealtime experience
-Staff members are encouraged to eat with those individuals who have a semi-dependent or independent eating skills
-Dining arrangements are based on a rational plan to meet the needs of the individuals served and the requirements of their programs
-Dining and serving arrangements provide for a variety of eating experiences (e.g., cafeteria and family style) and, when appropriate for the opportunity to make food selections with guidance
-Dining areas are designed to stimulate maximum self-development, social interaction, comfort and pleasure
-Food services provide a nourishing, well-balanced diet, consistent with local customs, to all individuals served
-Menus are planned to meet the food and nutrition needs of the individuals in accordance with the Recommended Dietary Allowances of the Food and Nutrition Board of the National Research Council, adjusted for age, sex and activity and disability
-Foods are prepared by methods that conserve nutritive value, enhance flavor, and enhance appearance
-Food is served:
  -As soon as possible after preparation, in order to conserve nutritive value
  -In an attractive manner
  -In appropriate quantity
  -At appropriate temperature

6. Residential Adults
   -The program provides individualized instruction on the skills that will help the adult make the transition to a less restricted environment:
      -Carrying out daily routines necessary to care for own needs
      -Developing effective communication with others
      -Eliminating or reducing socially maladaptive behaviors
   -The residential environment is as homelike as possible so that skills learned can be transferred or generalized into a less restricted environment
   -The resident has access to the community as appropriate
   -The program provides ready access to medical, dental, psychological, psychiatric, education and vocational assessment and treatment as required by the resident
   -Individuals are fed at a leisurely rate, and the time allowed for eating is such as to permit adequate nutrition, promote the development of self-feeding abilities, encourage socialization and provide a pleasant mealtime experience
   -Staff members are encouraged to eat with those individuals who have semi-dependent or independent eating skills
   -Dining arrangements are based on a rational plan to meet the needs of the individuals served and the requirements of their programs
   -Dining and serving arrangements provide for a variety of eating experiences (e.g., cafeteria and family style) and, when appropriate, for the opportunity to make food selections with guidance.
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   -Foods are prepared by methods that conserve nutritive value, enhance flavor, and enhance appearance
   -Food is served:
      -As soon as possible after preparation, in order to conserve nutrititive value
      -In an attractive manner
      -In appropriate quantity
      -At appropriate temperature
   -Staff is adequate to care for resident needs when well or sick and in addition:
      -Provide positive feedback for progress toward individual goals
      -Communicate on a regularly scheduled basis with staff providing vocational or other training
      -Provide structured activities and training for residents during residential hours

7. Leisure/Recreation Resources
   -The program provides individuals with age appropriate activities for leisure or recreation time

-Staff is adequate to teach leisure or recreation skills without neglecting others participating in the program
-The program utilizes community recreation resources to the maximum extent
-The program provides individuals with a choice of activities and teaches individuals to choose the type of activity in which to participate
-The program provides the opportunity for individuals to participate in recreation or leisure time activities with non-handicapped individuals
-The program has written plans and schedules for teaching:
  -Social interaction skills
  -Effective communication skills
  -Specific leisure time skills
  -Skills that develop and maintain physical health
-Activities provided by the program are appropriate to the ages and mental or physical abilities of the individuals participating

J. Social/Legal/Informational Services

1. Protective Social/Socio-Legal

Protection of Rights and Interests

-The program has supportive mechanism in place which assist autistic individuals in:
  -Obtaining the maximum degree of independence possible
  -Obtaining protection from exploitation, neglect or abuse by family, the service delivery system or society
  -Obtaining the most appropriate legal relationship
-The policy and procedures of the protective services insure strict adherence to the provision of due process:
-The service provides:
  -Counseling to autistic individuals, family and significant others as needed
  -Guidance
  -Follow along
  -Personal advocacy services

2. Follow along

-The follow along program implements a process that monitors the individuals progress and provides supportive services that assure movement toward long term goals
-The program educates individuals to seek follow along services when such services are needed to enhance their independence
-The follow along service assists with the transition to a new service as necessary
-The follow along service has written procedures that help to assure that the individual's rights are not violated

3. Information, Referral - Locating Resources and Services

-The resource information service is an easily identifiable point of contact for those seeking assistance
-The service:
  -Maintains current directories of resources
  -Has procedures of obtaining, cataloging, and updating information concerning resources

-Has written policies describing minimum standards for services to which referrals are made
-Works with other agencies and individuals to improve resource information and referral services
-Makes materials available for inservice training and community education

4. Consultation and Training
-Persons providing consultation and training have education in area of expertise and experience in working with autistic individuals
-Policy and procedures are in effect which allow agencies or programs using the services to provide feedback on the adequacy, appropriateness and effectiveness of the consultation and/or training
-Procedures are in effect that utilize the feedback from consumers to help provide a more valuable service

5. Follow-up
-Policies and procedures are in effect that protect the rights and privacy of individuals involved in the follow-up process
-Procedures are in effect which utilize information gathered in the follow-up process to enhance and improve future services
-Consultation to subsequent programs is provided as necessary to insure continuity of programming
-Other

The Autism Study
The Autism Study
The Autism Study

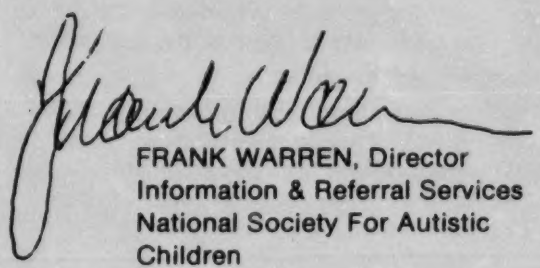
APPENDIX H

BROCHURE DESCRIBING THE AUTISM STUDY

We are pleased to hear that the School for Contemporary Education and Grafton School have received the Developmental Disabilities Unit Grant of the Department of Mental Health/Mental Retardation to study autism in Virginia.

Virginia, like many other states, is in desperate need of a statewide plan for service delivery to people who have autism.

We are most interested in the project and offer our full support and cooperation for this endeavor. We encourage your full cooperation.



FRANK WARREN, Director
Information & Referral Services
National Society For Autistic Children

The Autism Study
Grafton School, Box 469
Berryville, VA 22611
(703) 837-2491

WE NEED YOUR HELP • PLEASE RESPOND TODAY

Mail To: The Autism Study, c/o Grafton School, Box 469, Berryville, VA 22611

Parent's Name _____ Home Phone _____ Business Phone _____

Address _____ City _____ State _____ Zip _____

Individual with suspected autism _____ Date of Birth ____/____/____ Sex _____

Individual's School or Center _____ Address _____

☐ Please send me more information about your study. ☐ Please send me more brochures.

☐ I would be willing to provide more information about my child and the services he/she has been receiving.

WHAT IS THE AUTISM STUDY?

The Developmental Disabilities Unit of Virginia is working to identify all Virginia citizens with autism through a grant to Grafton School and the School for Contemporary Education.

We are asking everyone to help locate and count individuals having this disability so that the service needs of this group can be identified.

Since the disability of autism is often misunderstood, many individuals with autism may be misdiagnosed or placed in services that do not meet their special needs.

The Autism Study is the first step in the direction of providing better services in the future for this population. **Your** help is needed to identify persons with autism in Virginia, so that information can be gathered concerning their needs.

It is important that you respond immediately since the study will begin making written recommendations to the state in May, 1980. Having a complete count means that we can make recommendations to the Developmental Disabilities Unit concerning the service needs of Virginia citizens with autism.

Please help us help those who suffer from this disability.

WHAT IS AUTISM?

Autism is a life-long developmental disability which typically appears during the first three years of life.

The symptoms are caused by physical disorders of the brain and can occur by themselves or in combination with other disorders such as retardation, blindness, deafness, epilepsy, etc.

Characteristics of individuals with autism include:

1. *Problems affecting language: lack of speech, echolalic speech, delayed speech, poor comprehension, or failure to use speech for social communication.*
2. *Uneven development in many areas: including such things as social skills, fine motor skills or self help skills, sometimes with normal or superior memory skills or skills in non-language areas.*
3. *Unusual reactions to sensory experiences. The senses of pain, balance, smell, touch or taste might be affected. May appear not to see or hear persons or objects in the environment.*
4. *Abnormal ways of relating to people, objects, and events. Apparent social aloofness and indifference. Lack of appropriate peer interactions or friendships.*
5. *Preoccupation with sameness, ritualistic behavior, resistance to change, objects and toys used in unusual way.*

It is important that every individual with autism be identified, so that better services can be offered.

HOW CAN PARENTS HELP?

If you suspect that your child may be autistic or autistic-like, please take a few minutes to complete the attached form and send it in today. Upon receipt of your form, we will contact you requesting further information concerning your son or daughter. We will ask for your input on what service needs and support services you feel are important. All information received will be confidential. If you know other parents who have not received a brochure, give them our number and have them contact us immediately.

HOW CAN PROFESSIONALS HELP?

Please give a copy of this brochure to all parents or guardians of persons who may have the disability of autism. Encourage them to fill out the attached form and return it to us or ask for their permission for you to complete the form for them.

HOW CAN OTHERS HELP?

If you are aware of anyone suffering from this disability or anyone who seems to fit the described definition, pass this brochure along to the family and encourage them to complete the attached form.

THANK YOU FOR YOUR HELP!

If you have questions, please contact Lori DeZarn, Research Associate, (703) ~~873~~ 837-2491.

APPENDIX I

PARENTAL DESCRIPTIONS OF THEIR AUTISTIC CHILDREN
ON THE AUTISM CHECKLIST

Behavior Characteristic	Parent Responses		
	Number	Percentage	Percentage*
1. SOCIAL AND LANGUAGE PROBLEMS WERE PRESENT BEFORE CHILD 30 MONTHS OF AGE	120	92.3	
2. PROBLEMS AFFECTING LANGUAGE AND COMMUNICATION	130	100.0	
a. Mute, no speech	53	40.7	Same
b. Use words without attaching meaning to them	68	52.3	88.3
c. Echos or repeats what is said by others	74	56.9	96.1
d. Failure to use speech for social communication	100	76.9	Same
e. Problems with understanding communication from others	101	77.6	Same
f. Limited understanding of abstract terms or concepts	107	82.3	Same
g. Poor control of vocal pitch, volume and intonation	75	56.9	96.1
h. Lack of appropriate gestures (disassociation of gestures from language	73	56.1	Same
i. Repetitive, stereotyped, inflexible use of words and phrases	67	51.5	87.0
j. Prolonged confusion over the use of pronouns	53	40.7	68.8
k. Immature rhythms of speech	48	36.9	62.3
l. Uses jargon or television talk	44	33.8	57.1
		$\bar{x}$ = 55.2	74.1

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* Adjustment for mutism

APPENDIX I (continued)

Behavior Characteristic	Parent Responses	
	Number	Percentage
3. DISTURBED DEVELOPMENTAL RATES AND SEQUENCES	128	98.5
a. Normal coordination of the three developmental pathways (motor, social, adaptive) disrupted. Has uneven development across skill areas	113	86.9
b. Gross motor development normal while fine motor development is delayed	63	48.4
c. Motor development normal while social adaptive and cognitive development is delayed	75	57.6
d. Some cognitive skills developed at expected times while others were delayed or absent	80	61.5
e. Toileting and self-help skills not learned at appropriate level though motor skills appeared normal	79	60.7
f. Some skills appeared at expected times during development and then disappeared	59	45.3
g. Development in some non-language skill areas at normal or superior levels of development (music, math, mechanical abilities, puzzling skills) while language skills remain far below expected levels	73	56.1
		$\bar{x}$ = 69.4
4. UNUSUAL OR ABNORMAL RESPONSES TO SENSORY STIMULI	123	94.6
a. Auditory symptoms: seems not to hear some sounds or some sounds may seem painful (though hearing assessed as normal)	76	58.4
b. Does not react to pain or cold as expected	50	38.4
c. Has unusual responses to smell, taste, or texture	73	56.1

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Behavior Characteristic	Parent Responses	
	Number	Percentage
4. UNUSUAL OR ABNORMAL RESPONSES TO SENSORY STIMULI (continued)		
d. Has odd sense of balance - may hold body in unusual way, may whirl without getting dizzy	70	53.8
e. Has frequent repetitive movements, such as hand shaking and spinning	94	72.3
f. Visual symptoms: may appear to notice visual details rather than whole object or picture, may be fascinated with one visual stimuli such as lights	87	66.9
Smells or mouths things in the environment at an abnormally high rate	79	60.0
h. Has abnormal response to being touched	69	53.0
		$\bar{x}$ = 57.4
5. ABNORMAL WAYS OF RELATING TO PEOPLE, OBJECTS AND EVENTS	123	94.6
a. Abnormalities of social development	121	93.0
1. Isolates self from others	95	73.0
2. Disinterested in people	70	53.8
3. Apathetic & unresponsive; shows no desire to be held	62	47.6
4. Poor eye contact, looks "through" people	97	74.6
5. Does not pick up social cues of others	81	62.3
6. Fails to develop persistent relationships	84	64.6
7. Does not reciprocate in social interactions or social conversation	98	75.3
8. Does not initiate interaction with others	90	69.2

(APPENDIX I (continued)

Behavior Characteristic	Parent Responses	
	Number	Percentage
5. ABNORMAL WAYS OF RELATING TO PEOPLE, OBJECTS AND EVENTS (continued)		
b. Ritualistic behaviors	116	89.2
1. Preoccupation with sameness	85	65.3
2. Has rituals regarding schedules or objects in the environment	85	65.3
3. Resists change	98	75.3
c. Play	110	84.6
1. Has no imaginative play	86	66.1
2. Objects and toys used in unusual ways	86	66.1
		$\bar{x}$ = 73.1

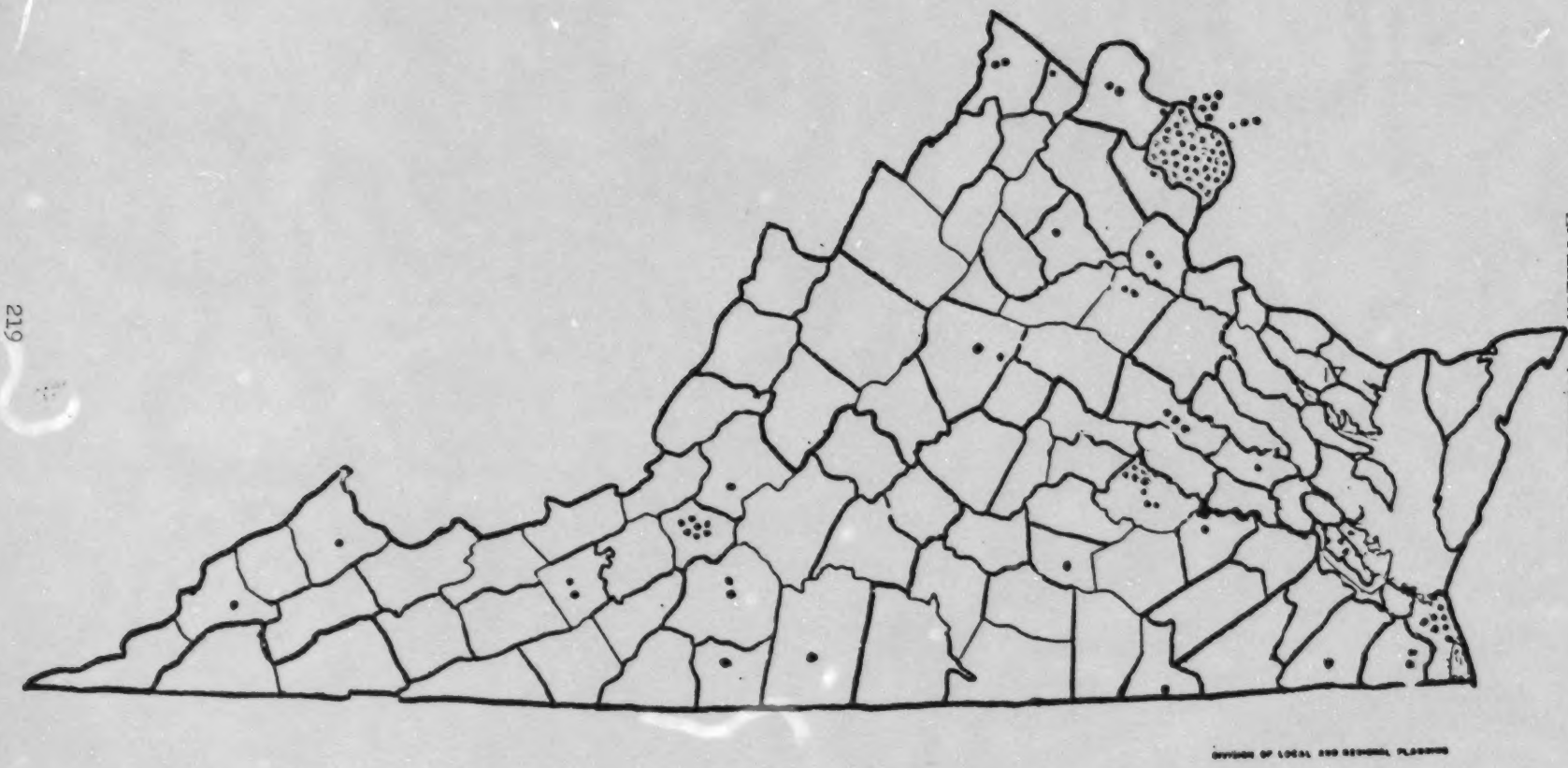
APPENDIX J

FREQUENCY OF RESPONSES TO THE PARENT SURVEY
ACCORDING TO COUNTY/CITY

Counties	Frequency	Percentage
Albemarle	1	0.8
Arlington	4	3.4
Botetourt	1	0.8
Buchanan	1	0.8
Chesterfield	3	2.5
Culpeper	1	0.8
Fairfax	28	23.7
Franklin	2	1.7
Greensville	1	0.8
Hanover	3	2.5
Henrico	1	0.8
Henry	1	0.8
Loudoun	3	2.5
Montgomery	1	0.8
New Kent	1	0.8
Nottoway	1	0.8
Prince Wm.	2	1.7
Pulaski	2	1.7
Roanoke	6	5.1
Stafford	2	1.7
Wise	1	0.8

APPENDIX J (continued)

City	Frequency	Percentage
York	1	0.8
Alexandria	7	5.9
Charlottesville	1	0.8
Chesapeake	2	1.7
Fairfax	4	3.4
Falls Church	1	0.8
Fredericksburg	1	0.8
Hampton	1	0.8
Hopewell	1	0.8
Martinsville	1	0.8
Newport News	2	1.7
Norfolk	3	2.5
Richmond	7	5.9
Salem	1	0.8
Suffolk	1	0.8
Va. Beach	7	5.9
Winchester	2	1.7
?	8	6.8
Total	118	100.0



The Location of 118 Persons with Autism in Virginia

APPENDIX K

PERCENTAGE OF DIAGNOSTIC LABELS AND LISTING OF "OTHER" DIAGNOSES AS REPORTED BY PARENTS

Diagnostic Label	Code	Frequency	Relative Percentage	Relative Percentage	Cumulative Frequency
Autistic	1.	31	26.3	27.7	27.7
Autistic-like	2.	32	27.1	28.6	56.3
"Other"*	3.	8	6.8	7.1	63.4
1, 2	4.	5	4.2	4.5	67.9
1, 3	5.	10	8.5	8.9	76.8
2, 3	6.	15	12.7	13.4	90.2
1, 2, 3	7.	11	9.3	9.8	100.0
Missing	0.	6	5.1	Missing	
	Total	118	100.0	100.0	

*"Other" diagnostic labels assigned to autistic persons as reported by parents:

Mentally Retarded
Language Delayed
Severely Learning Disabled
Multiply Learning Disabled
Borderline Retarded
Severe Mental Retardation with Autistic Behaviors
Hydrocephalic
Legge's Perthers Disease
Hearing Impaired
Behavior Problem
Undetermined
Childhood Schizophrenia
Brain Damaged
Learning Disabled
Severe Mental Retardation
Educable Mental Retardation
Schizophrenic
Emotionally Disturbed
Metabolic Disorder
Deaf
Psychotic
Profoundly Retarded
Trainable Mentally Retarded
Lead Poisoning
Aphasic

APPENDIX L

DIAGNOSTIC CENTERS UTILIZED BY PARENTS

Facility	City	State
Kimages Preschool	Charles City	Virginia
Tidewater Association for Retarded Citizens	Norfolk	Virginia
C&E Clinic at Medical College of Virginia	Richmond	Virginia
Fairfax County and Private Professionals		Virginia
Mental Health Center	Alexandria	Virginia
George Mason Clinic	Arlington	Virginia
Roanoke Valley Speech & Hearing Center	Roanoke	Virginia
Roanoke Valley Psychiatric Center	Roanoke	Virginia
Crossroads Mental Health Services	Burkeville	Virginia
Children's Rehabilitation Center	Leesburg	Virginia
Crater Child Development Center	Petersburg	Virginia
Wise County Schools	Wise	Virginia
Medical College of Virginia	Chapel Hill	Virginia
Psychiatric Associates	Salem	Virginia
Private Physician	Alexandria	Virginia
Human Resource Institute	Norfolk	Virginia
Chesterfield County Schools		Virginia
Child Development Center	Stephens City	Virginia
Child Guidance Clinic	Richmond	Virginia
Arlington County Diagnostic Clinic	Falls Church	Virginia
Behavior Resources	Winchester	Virginia
Easter Seal Center	Virginia Beach	Virginia
Diagnostic & Evaluation Center		Virginia
Tidewater Rehabilitation Institute	Norfolk	Virginia
Children's Rehabilitation Center	Charlottesville	Virginia
Virginia Treatment Center	Richmond	Virginia
Samuel A. Anderson Clinic	Richmond	Virginia
Fairfax County School System	Alexandria	Virginia
Consultation and Evaluation Center	Richmond	Virginia
Private Physician	Alexandria	Virginia
Children's Development Center	Fredericksburg	Virginia
DeJarnette School	Staunton	Virginia
Community Health Clinic	Norfolk	Virginia
Test & Evaluation Clinic	Richmond	Virginia
Community Mental Health	Falls Church	Virginia
Bayberry Hospital	Hampton	Virginia
Diagnostic Clinic	Arlington	Virginia
Child Development Clinic	Richmond	Virginia
Private Physician	Richmond	Virginia
Mental Health Clinic	Radford	Virginia

APPENDIX L (continued)

Facility	City	State
Private Physician	Roanoke	Virginia
University of Virginia	Charlottesville	Virginia
Medical College of Virginia	Richmond	Virginia
Area A Mental Health Clinic	Washington	D.C.
Children's Hospital	Washington	D.C.
Private Physician	Washington	D.C.
Children's Diagnostic Clinic	Washington	D.C.
Private Physician	Washington	D.C.
Georgetown Children's Diagnostic Clinic	Washington	D.C.
Hillcrest Children's Center	Washington	D.C.
Walter Reed Army Hospital	Washington	D.C.
Georgetown University Hospital	Washington	D.C.
Children's Brain Research Center	Washington	D.C.
Gallaudet College	Washington	D.C.
Children's Hospital Hearing and Speech	Washington	D.C.
Georgetown Child Development Center	Washington	D.C.
National Institute of Psychology	Washington	D.C.
Gale Clinic	Washington	D.C.
Private Physician	Washington	D.C.
Montgomery County Mental Health Center		Maryland
Kennedy Institute	Baltimore	Maryland
Johns Hopkins Hospital	Baltimore	Maryland
Dr. Leo Kanner	Baltimore	Maryland
Eastern TEACCH Center	Greenville	North Carolina
TEACCH Center	Chapel Hill	North Carolina
Yale University	New Haven	Connecticut
Western Psychiatric Institute	Pittsburgh	Pennsylvania
CNR	Morton	Pennsylvania
Maine Medical Center	Portland	Maine
U.S.A.F. Medical Center		Illinois
U.S. Army	San Antonio	Texas
U.S. Army Tripler Medical Center	Honolulu	Hawaii
Boston Children's Hospital	Boston	Massachusetts
University of Vermont	Burlington	Vermont
Linwood Children's Center		?
Wine City Schools		?
Mental Health Clinic		?
Devonshire Diagnostic Center		?

APPENDIX M

HISTORY OF SERVICES FROM PARENT SURVEY (N = 83)

SUBJECT #	AGE	NUMBER SCHOOLS ATTENDED	NUMBER SCHOOLS ATTENDED IN VA.	AVERAGE LENGTH OF STAY (YEARS)	REASONS FOR LEAVING
1.	15	4	4	6.66	age limit, age limit recommendation
2.	6	4	4	1.16	psychologist left, enrolled elsewhere, enrolled elsewhere
3.	10	1	1	3.25	therapist left
4.	16	2	2	3.5	to go to public school
5.	14	4	4	2.33	another school, another school, another school
6.	24	6	5	5.6	age limit, moved out of town, moved to Va., age limit, transferred
7.	14	2	2	5	age limit
8.	16	4	3	1	insurance problem, financial problem, insurance problem
9.	13	5	5	2	program phased out, residential program detrimental, insurance problem, program unsuitable
10.	16	3	1	2.5	job transfer, job transfer
11.	14	5	4	2.25	age limit, age limit, left the country, returned to U.S.
12.	17	5	4	2.1	age limit, relief for parents, enrolled in research program, too large to handle
13.	18	3	2	3.5	to bring him closer to home, cost
14.	20	6	5	1.8	county discontinued service, went out of business, return to county school, return to private school

APPENDIX M (continued)

SUBJECT #	AGE	NUMBER SCHOOLS ATTENDED	NUMBER SCHOOLS ATTENDED IN VA.	AVERAGE LENGTH OF STAY (YEARS)	REASONS FOR LEAVING
15.	14	3	3	3.33	to enroll in county service, mainstreamed
16.	20	5	5	3.5	poor services, aggression and improper placement
17.	18	1	1	8	
18.	13	4	2	2.5	inappropriate service, left to return to U.S., needed more service
19.	17	8	7	1.5	teacher moved, too far to travel, did not feel this was a good placement, self-abusive, new school built
20.	16	6	5	1.4	moved, end of 2 year program
21.	17	4	4	1.66	too far, inappropriate placement
22.	16	5	2	6	accepted in public school, moved out of state, moved to advanced program
23.	16	1	1	3.25	placement aggravated condition
24.	19	3	1	7.5	moved, day care recommended
25.	9	5	1	1.25	program too advanced, moved, moved, moved
26.	11	4	4		
27.	7	5	5	1.5	at a "crossroads", tests over, evaluation over
28.	25	5	4		program was recommended, going to a home, requested to leave, doctor recommended, age limit
29.	6	6	5	1.4	special tutoring needed, public special ed. available, transfer, transfer, transfer

APPENDIX M (continued)

SUBJECT #	AGE	NUMBER SCHOOLS ATTENDED	NUMBER SCHOOLS ATTENDED IN VA.	AVERAGE LENGTH OF STAY (YEARS)	REASONS FOR LEAVING
30.	7	6	0	1	moved, no longer needed physical therapy, not enough structure to meet needs, could not meet needs, referred
31.	6	2	2	1.4	no autistic program
32.	5	5	5	1.5	
33.	12	4	4	3.5	sold school, inappropriate placement
34.	5	2	1	1.5	inadequate service, inadequate service
35.	9	5	4	1	moved, moved, too disturbed
36.	6	4	4	1	inadequate service, started in home base program, age limit
37.	38	1	1	1	completed course of treatment
38.	8	4	4	1	eligible for pre-school
39.	7	6	3	.7	age limit, moved, moved, transferred, insurance problem, asked to leave
40.	12	7	7	1.25	
41.	8	5	5	1	
42.	6	6	2	.8	inadequate placement
43.	8	1	1	.5	diagnosed autistic
44.	28	3	2	7	age limit, cost
45.	22	3	2	3.66	cost, to enter public school program, age limit
46.	22	16	16	1.88	had wrong diagnosis, to attend public school, transfer, unhappy with progress

APPENDIX M (continued)

SUBJECT #	AGE	NUMBER SCHOOLS ATTENDED	NUMBER SCHOOLS ATTENDED IN VA.	AVERAGE LENGTH OF STAY (YEARS)	REASONS FOR LEAVING
47.	11	5	5	1	to attend public school, discharge, withdrew
48.	6.5	1	1	1	poor services
49.	6	2	2	2.2	inadequate service, age limit
50.	25	5	2	2.32	
51.	8	4	4	1.66	recommended by special ed.
52.	38	3	1	11	foster parents retired, school moved
53.	5.5	2	1	1	transfer, end of school year, graduated
54.	3.5	2	2	1	to enter pre-school
55.	8	1	1	.6	evaluation completed
56.	10	5	1	2	psychiatric center recommended, to attend public school, moved
57.	10	2	1	2	moved
58.	23	7	5	3	transfer, discharged, inadequate service, completed program, age limit
59.	4	1	1	1	moved
60.	10	6	6	1	inappropriate program, ineffective program, program discontinued, age limit
61.	12	8	8	2	entered private school, reentered public school, public school unable to cope
62.	10	4	4	2	doctor's suggestion, doctor's suggestion
63.	8	1	1	3	

APPENDIX M (continued)

SUBJECT #	AGE	NUMBER SCHOOLS ATTENDED	NUMBER SCHOOLS ATTENDED IN VA.	AVERAGE LENGTH OF STAY (YEARS)	REASONS FOR LEAVING
64.	11	1	1	2.4	was not responding
65.	29	1	1	5.2	unsuitable placement
66.	12	3	1	3.16	transferred, transferred
67.	25	8	4	3.16	graduated, came to a "parting of ways", recommendation of psychologist, transportation problems
68.	9	3	3	1.33	to enter public school, moved
69.	8	3	3	1	to enter public school special ed. program
70.	9	2	2	2	no progress
71.	9	2	2	2	entered autistic program
72.	7	4	1	2.25	grant ran out, inappropriate placement
73.	25	6	1	2	transferred, transferred, transferred, transferred
74.	11.5	2	2	1	school closed permanently
75.	15	4	4	2.33	to enter public school class for autistic, transferred, age limit
76.	23	9	7	2	moved, moved, referred, school closed, school closed, behavior poor, asked to leave
77.	6	3	3	1.25	age limit, age limit, age limit
78.	10	3	3	2.5	inadequate services, school closed
79.	24	6	6	2.25	inappropriate placement, program ended, program ended

APPENDIX M (continued)

SUBJECT #	AGE	NUMBER SCHOOLS ATTENDED	NUMBER SCHOOLS ATTENDED IN VA.	AVERAGE LENGTH OF STAY (YEARS)	REASONS FOR LEAVING
80.	3	2	2		
81.	5	2	2	1	city pre-school moved to county
82.	9	3	3	1.5	age limit, inappropriate services
83.	10	4	4	1.16	age limit, needed more therapy, smaller class, inadequate services
Mean ($\bar{x}$) =		3.96	3.13	1.75	

APPENDIX N

PARENT RESPONSES TO THE CONTINUUM OF SERVICES

My child:

	Needs This Service		I am Satisfied With This Service				Will Probably Need in Future	
	Yes	No	Yes	No	DK	NR	Yes	No
I. Identification								
1. Diagnosis: Formal identification of autism	27.3	27.4	71.4°	5.7	2.8	20.0	85.7	14.3
2. Evaluation: Assessment for purposes of individual program planning	35.9	6.5	67.3°	2.0	8.1°	22.4	96.4°	3.6
II. Education, Training, or Treatment/Growth Services								
A. Language Development								
1. Language training	26.8	7.3	60.3°	15.0°	13.2°	24.5	95.4*	5.5
2. Speech therapy	26.4	7.9	46.2	20.8°	8.9°	17.9	89.1	10.9
3. Sign language	20.9	34.9	50.0	10.7°	17.8°	21.4	68.9	31.1*
4. Total communication system	41.7*	10.7	53.5	10.7°	10.7	25.0	87.0	13.0
5. Other nonverbal language systems	28.5	34.3	44.4	5.5	16.6°	33.3°	78.1	21.9*
B. Socialization								
1. Play Skills	26.2	5.9	54.5	12.1°	9.0°	24.2	94.1°	5.9
2. Peer interaction	30.8	1.9	47.9	13.6°	10.9°	23.3	98.1*	1.9
3. Interaction w/authority	22.5	4.1	56.7	16.4°	8.9°	17.9	96.1°	3.9
4. Group interaction	33.0	1.9	50.0	17.6°	8.8°	23.5	96.2°	3.8
5. Emotional expression	32.7	6.1	55.7	17.3°	9.6°	17.3	97.9°	2.1
6. Use of leisure time	42.7*	6.3	41.5	15.1°	7.5°	20.7	98.2*	1.8
7. Use of community resources	40.5*	9.0	44.7	15.8°	13.2°	26.3°	98.2*	1.8
8. Money management	37.8	27.1	61.9°	4.8	14.3°	19.0	95.4°	4.6

* = + 1 S. D. (over 85%)
° = 0 - 1 S. D. (50-84%)
DK = Don't know
NR = No Response

APPENDIX N (continued)

My child:

B. Socialization (continued)	Needs This Service		I am Satisfied With This Service				Will Probably Need in Future	
	Yes	No	Yes	No	DK	NR	Yes	No
9. Use of public transportation	28.3	40.7*	56.5	17.4°	4.3	21.7	91.9°	8.1
10. Sex education	34.7	41.7*	33.3	0.0	50.0	16.7	90.5	9.5
11. Planned experiences with non-handicapped individuals	48.4*	7.5	63.6°	3.0	9.1°	24.2	96.7°	3.3
C. Personal Independent Skills								
1. Grooming	23.4	10.7	47.6	9.5	7.1	35.7°	95.8°	4.2
2. Hygiene	24.0	7.0	60.3°	4.7	9.5°	25.4	95.2°	4.8
3. Housekeeping	26.8	11.3	56.2	8.3	8.3°	27.1°	98.0°	2.0
4. Care of personal items	29.8	11.5	57.5°	10.0	5.0	27.5°	97.8°	2.2
5. Independent living	29.9	28.6	57.9°	10.5°	5.3	26.3°	94.4°	5.6
D. Preacademic Instruction (Readiness)	20.4	21.7	64.1°	2.6	7.7°	25.7	90.7	9.3
E. Academic Instruction								
1. Reading	24.4	22.0	63.9°	8.3	2.8	25.0	86.5	13.5
2. Language Arts	24.7	22.1	55.6	13.9°	5.6	25.0	89.8	10.2
3. Math	23.1	20.5	60.0°	7.5	5.0	27.5°	92.0°	8.0
4. Social Studies	23.9	43.2	60.0°	15.0°	0.0	25.0	90.6	9.4
5. Science	26.0	30.4	72.2°	11.1°	0.0	16.7	90.6	9.4
6. Physical Education	23.8	10.3	52.1	20.8°	4.2	22.9	94.0°	6.0
F. Specific Programming to Remediate Maladaptive Behaviors	39.6	7.7	54.8	14.3°	9.5°	21.4	96.4°	3.6
G. Prevocational Instruction	39.4	25.4	58.8°	23.5°	0.0	17.6	98.6*	1.4
H. Vocational Instruction	43.1*	35.4	44.4	11.1°	11.1°	33.3°	98.5*	1.5

* = + 1 S. D. (over 85%)
o = 0 - 1 S. D. (50-84%)
DK = Don't Know
NR = No Response

APPENDIX N (continued)

My child:

	Needs This Service		I am Satisfied With This Service				Will Probably Need in Future	
I. Expressive Development	Yes	No	Yes	No	DK	NR	Yes	No
1. Dance	35.0	21.2	60.0°	16.0°	4.0	20.0	87.8	12.2
2. Music	25.5	13.3	53.3	13.3°	4.4	28.9°	95.7°	4.3
3. Art	26.1	10.9	58.3°	10.4°	8.5°	22.9	97.8°	2.2
III. Related Support Services								
A. Transportation (Travel to & from services)	13.1	14.8	61.1°	16.7°	1.9	20.4	98.4*	1.6
B. Recreation (Activities for leisure time)	40.6*	6.2	48.9	13.3°	11.1°	26.7°	100.0*	0.0
C. Counseling - professional guidance of the individual for behavioral and emotional problems	39.8*	20.4	58.6°	6.9	10.3°	24.1	92.6°	7.4
D. Psychotherapy - treatment of the individual aimed at enhancing and changing intra-psychic or psychological functioning	38.1*	31.6	55.6	22.2°	16.7°	5.6	85.1	14.9
E. Psychiatric consultation - to program staff regarding individual served	35.8	25.9	57.1°	4.8	14.3°	23.8	82.9	17.1*
F. Psychological consultation to program staff regarding individual served	40.3*	15.9	66.7°	6.0	9.1°	18.2	92.5°	7.5
G. Physical or occupational therapy evaluating, improving, developing or restoring physical functions	35.2	20.5	63.3°	3.3	13.3°	20.0	82.2	17.8*
H. Speech pathology or language training - evaluation, consultation and individual remediation or development	34.4	3.0	50.0	12.1°	12.1°	25.9	100.0*	0.0

* = + 1 S. D. (over 85%)
o = 0 - 1 S. D. (50-84%)
DK = Don't know
NR = No Response

APPENDIX N (continued)

My child:

	Needs This Service		I am Satisfied With This Service				Will Probably Need in Future	
	Yes	No	Yes	No	DK	NR	Yes	No
I. Social work - evaluation and mobilizing community resources, social case work with families	39.8*	22.8	66.7°	8.3	4.2	20.8	88.2	11.8
J. Audiological - evaluation and consultation	22.0	39.0	53.8	15.4°	0.0	30.8°	71.4	28.6*
K. Health - medical	16.9	20.0	58.5°	11.3°	1.9	28.3°	89.6	10.4
L. Dental	20.2	24.8	60.0°	8.9	0.0	31.1	90.5	9.5
M. Music, dance or art therapy	52.6	18.0	65.8°	2.6	5.3	26.3°	94.2°	5.8
N. Adaptive physical education	27.9	17.4	59.0°	20.5°	5.1	15.4	90.9	9.1
O. Nutritional/dietary evaluation and counseling	35.9	33.3	58.9°	26.3°	0.0	15.8	81.4	18.6*
IV. Family Services								
A. Communication - ongoing formal or informal communication	36.7	12.2	72.5°	5.0	5.0	17.5	92.5°	7.5
B. Training - instruction to family in techniques for assisting individual with autism	55.3*	14.5	65.4°	0.0	7.7	26.9°	93.0°	7.0
C. Counseling - guidance to family regarding the emotional impact of having an individual with autism	45.2*	32.3	66.7°	0.0	5.6	27.8°	77.5	22.5*
D. Respite - temporary or emergency care	33.7	39.3	50.0	16.7°	5.6	27.8°	89.7	10.3
E. Support								
1. Regular group meetings			69.0°	3.4	6.8	20.7		
2. Parent - parent support	37.1	22.4	58.1°	12.9°	6.5	22.6	86.6	13.2
F. Advocacy - informing families of their rights and of relevant organizations	38.5	20.4	61.1°	8.3	8.3°	22.2	88.6	11.4

* = + 1 S. D. (over 85%)
o = - 1 S. D. (50-84%)
DK = Don't Know
NR = No Response

My child:

	Needs This Service		I am Satisfied With This Service				Will Probably Need in Future	
	Yes	No	Yes	No	DK	NR	Yes	No
V. Employment Services								
A. Sheltered employment - work adjustment and job skill training	26.9	50.8*	42.9	14.3°	0.0	42.9°	97.0°	3.0
B. Supervised/subsidized employment - support for employment of the chronically disabled in the natural environment	27.9	54.1*	50.0	0.0	0.0	50.0°	92.9°	7.1
C. Vocational rehabilitation-evaluation, training and competitive job placement	21.6	53.9*	25.0	0.0	0.0	75.0°	93.8°	6.2
VI. Living Services								
A. Adult day care - supervised care with some training	15.2	57.0*	58.3°	8.3	8.3°	25.0	93.6°	6.4
B. Child day care - supervised care with some training	23.2	52.5*	80.0°	0.0	0.0	20.0	78.8	21.2*
C. Transitional living arrangements	15.6	65.6*	50.0	0.0	0.0	50.0°	83.3	16.7*
D. Permanent special living arrangements - group home, apartment living, specialized foster care	22.4	52.3*	50.0	0.0	0.0	50.0°	87.9	12.1
E. Residential services for children - 24 hour out of home care	20.0	46.7*	68.8°	0.0	6.3	25.0	73.5	26.5*
F. Residential services for adults - 24 hour out of home care	22.9	50.0*	60.0°	10.0	0.0	30.0	88.4	11.6
G. Leisure/recreational resources	45.9	14.1	50.0	11.6°	11.6°	26.9°	98.0°	2.0
x =	30.9	23.5	56.7	10.1	7.3	25.9	91.1	8.9
S.D.=	8.9	15.9	- -	- -	- -	- -	7.0	6.8

* = + 1 S. D. (over 85%)
o = 0 - 1 S. D. (50-04%)
DK = Don't Know
NR = No Response

NOTES: 1.) The data in the categories of "Needs This Service" does not add up to 100% since respondents frequently omitted information from this part of the survey, thus, the percentages are actual rather than adjusted percentages.

2.) The symbol "o" in the category "I am Satisfied With This Service" reflects that the percentage figure is above the average response; standard deviations were not calculated for this category.

APPENDIX O

A CHI SQUARE ANALYSIS OF THE DISTRIBUTION OF AUTISTIC INDIVIDUALS BY AGE AND HEALTH SERVICE AREAS (HSAs) IN VIRGINIA

Count Row Pct Col Pct Tot Pct	Area I 1.	Area II 2.	Area III 3.	Area IV 4.	Area V 5.	Out of State 6.	Row Total
1.	0	2	3	6	2	3	16
	0.0	12.5	18.8	37.5	12.5	18.8	13.6
0-5 yrs	0.0	4.1	17.6	33.3	11.8	37.5	
	0.0	1.7	2.5	5.1	1.7	2.5	
2.	6	19	10	8	11	2	56
	10.7	33.9	17.9	14.3	19.6	3.6	47.5
6-12 yrs	66.8	38.8	58.8	44.4	64.7	25.0	
	5.1	16.1	8.5	6.8	9.3	1.7	
3.	2	15	3	3	3	2	28
	7.1	53.6	10.7	10.7	10.7	7.1	23.7
12-21 yr	22.2	30.6	17.6	16.7	17.6	25.0	
	1.7	12.7	2.5	2.5	2.5	1.7	
4.	1	13	1	1	1	1	18
over	5.6	72.2	5.6	5.6	5.6	5.6	15.3
21 yrs.	11.1	26.5	5.9	5.6	5.9	12.5	
	0.8	11.0	0.8	0.8	0.8	0.8	
Column	9	49	17	18	17	8	118
Total	7.6	41.5	14.4	15.3	14.4	6.8	100.0

17 out of 24 (70.8%) of the valid cells have expected cell frequency less than the 0.5 minimum. Expected cell frequency = 1.085
Chi square = 26,37372 with 15 degrees of freedom
Significance = 0.0343

APPENDIX F

ESTIMATED AUTISTIC AND AUTISTIC-LIKE SCHOOL AGED INDIVIDUALS
USING RESEARCH CRITERIA AND DESCRIPTIVE SURVEY RESPONSES

Public Schools County	(a) Sp.Ed.	(b) Total	(c) Projected Autistic	(d) Estimated Autistic-Like	(e) Identified Autistic	(f) Number Served	(g) Maximum Number
001 Accomack	118	5,501	8.3	1*	1*	-	1
002 Albemarle	246	9,391	14.1	-	0	-	0
003 Alleghany	26	3,209	4.8	NR	NR	-	-
004 Amelia	15	1,604	2.4	0	0	-	0
005 Amherst	98	5,393	8.1	2	0	-	2
006 Appomattox	27	2,698	4.0	1	0	-	1
007 Arlington	364	15,152	22.7	-	0	20	20
008 Augusta	169	10,781	16.2	0	0	-	0
009 Bath	39	1,090	1.6	0	0	-	0
010 Bedford	142	8,011	12.0	2	2	2	2
011 Bland	22	1,267	1.9	0	0	-	0
012 Botetourt	105	4,741	7.1	NR	NR	-	-
013 Brunswick	76	3,122	4.7	4	0	4	4
014 Buchanan	110	8,848	13.3	3	0	2	3
015 Buckingham	8	2,551	3.8	1	0	-	1
016 Campbell	129	9,521	14.3	NR	NR	-	-
017 Caroline	80	3,859	5.8	NR	NR	-(3)	-
018 Carroll	70	5,093	7.6	7	0	-	7
019 Charles City	31	1,454	2.2	0	0	-	0
020 Charlotte	60	2,663	4.0	1	0	-	1

APPENDIX P (continued)

Public Schools County		(a) Sp.Ed.	(b) Total	(c) Projected Autistic	(d) Estimated Autistic-Like	(e) Identified Autistic	(f) Number Served	(g) Maximum Number
021	Chesterfield	470	33,351	50.0	-	-	-	-
022	Clarke	23	1,797	2.7	0	0	-(1)	0
023	Craig	20	758	1.1	NR	NR	-	-
024	Culpeper	57	4,600	6.9	NR	NR	-	-
025	Cumberland	19	1,667	2.5	-	0	-	-
026	Dickenson	37	4,438	6.7	2	0	1	2
027	Dinwiddie	173	4,636	7.0	1	0	-	1
028	Essex	34	1,689	2 5	3	1	1	3
029	Fairfax	3,658	127,189	190.8	NR	NR	36	36
030	Fauquier	100	7,408	11.1	NR	NR	-	-
031	Floyd	35	2,127	3.2	0	0	5(2)	5
032	Fluvanna	45	2,181	3.3	NR	NR	-	-
033	Franklin	157	4,945	10.4	1	2	3	3
034	Frederick	210	7,402	11.1	NR	NR	-(1)	-
03	Giles	63	3,766	5.6	1	1	-(2)	1
036	Gloucester	55	3,858	5.8	6	0	-	6
037	Goochland	57	2,017	3.0	NR	NR	-	-
038	Grayson	38	2,342	3.5	NR	NR	-	-
039	Greene		1,610	2.4	0	0	-	0
040	Greensville	249	3,438	5.2	NR	NR	-	-

APPENDIX P (continued)

Public Schools County	(a) Sp.Ed.	(b) Total	(c) Projected Autistic	(d) Estimated Autistic-Like	(e) Identified Autistic	(f) Number Served	(g) Maximum Number
041 Halifax	90	6,951	10.4	-**	-**	3	3
042 Hanover	249	10,505	15.8	1	0	1	1
043 Henrico	774	32,389	48.6	NR	NR	-	-
044 Henry	211	11,634	17.5	NR	NR	-	-
045 Highland	5	446	.7	2	0	2	2
046 Isle of Wight	53	4,172	6.3	1	1	-	1
048 King George	49	2,345	3.5	NR	NR	-(3)	-
049 King Queen	40	997	1.5	0	0	-	0
050 King William	72	1,434	2.2	0***	0***	-	0
051 Lancaster	20	1,680	2.5	NR	NR	-	-
052 Lee	18	5,661	8.5	NR	NR	-	-
053 Loudoun	254	13,447	20.2	2	1	-	2
054 Louisa	108	3,589	5.4	2	1	-	2
055 Lunenburg	24	2,471	3.7	NR	NR	-	-
056 Madison	32	1,997	3.0	NR	NR	-	-
057 Mathews	22	1,311	2.0	NR	NR	-	-
058 Mecklenburg	114	5,861	8.8	NR	NR	-	-
059 Middlesex	25	1,266	1.9	NR	NR	-	-
060 Montgomery	244	9,166	13.7	NR	NR	-(2)	-
062 Nelson	55	2,455	3.7	0	0	-	0
063 New Kent		1,710	2.6	NR	NR	-	-

APPENDIX P (continued)

Public Schools County		(a) Sp.Ed.	(b) Total	(c) Projected Autistic	(d) Estimated Autistic-Like	(e) Identified Autistic	(f) Number Served	(g) Maximum Number
065	Northampton	29	2,526	3.8	*	*	-	-
066	Northumberland	33	1,513	2.3	NR	NR	-	-
067	Nottoway	52	2,790	4.2	NR	NR	-	-
068	Orange	149	3,715	5.6	2	1	-	2
069	Page	9	3,765	5.6	1	0	-	1
070	Patrick	35	3,463	5.2	NR	NR	-	-
071	Pittsylvania	345	13,474	20.2	NR	NR	-	-
072	Powhatan	117	2,432	3.6	1	0	-	1
073	Prince Edward	245	2,211	3.3	0	0	-	0
074	Prince George	42	5,364	8.0	NR	NR	-	-
075	Prince William	505	35,608	53.4	6	0	4	6
077	Pulaski	193	7,589	11.4	5	1	-(2)	5
078	Rappahannock	13	1,135	1.7	NR	NR	-	-
079	Richmond	10	1,343	2.0	NR	NR	-	-
080	Roanoke	443	19,194	29.1	8	5	9	9
081	Rockbridge	121	3,694	5.5	0	1	-	1
082	Rockingham	45	10,110	15.2	NR	NR	-	-
083	Russell	97	6,606	9.9	NR	NR	-	-
084	Scott		5,087	7.6	NR	NR	-	-
085	Shenandoah	87	5,176	7.8	0	0	-	0
086	Smyth	70	6,744	10.1	NR	NR	-	-

APPENDIX P (continued)

Public Schools County		(a) Sp.Ed.	(b) Total	(c) Projected Autistic	(d) Estimated Autistic-Like	(e) Identified Autistic	(f) Number Served	(g) Maximum Number
087	Southampton	187	3,183	4.8	0	0	-	0
088	Spotsylvania	134	8,529	12.8	NR	NR	-(3)	-
089	Stafford	305	9,742	14.6	5	5	8(3)	8
090	Surry	3	1,288	1.9	0	0	-	0
091	Sussex	9	2,327	3.5	NR	NR	-	-
092	Tazewell	144	10,750	16.1	NR	NR	-	-
093	Warren	86	3,993	6.0	1	0	1	1
094	Washington	42	9,371	14.1	1	0	-	-
095	Westmoreland	52	2,294	3.4	NR	NR	-	-
096	Wise	49	9,885	14.8	NR	NR	-	-
097	Wythe	77	5,294	7.9	NR	NR	-	-
098	York	93	8,843	13.3	3	2	3	3
County Totals		13,765	669,895	1004.8	77	24	85	128

APPENDIX P (continued)

Public Schools City		(a) Sp.Ed.	(b) Total	(c) Projected Autistic	(d) Estimated Autistic-Like	(e) Identified Autistic	(f) Number Served	(g) Maximum Number
101	Alexandria	142	10,831	16.2	10	3	-	10
102	Bristol	32	3,464	5.2	0	0	-	-
103	Buena Vista	59	1,458	2.2	0	0	-	0
104	Charlottesville	199	5,073	7.6	0	0	-	0
136	Chesapeake - City	380	25,005	37.5	4	0	4	4
105	Clifton Forge	8	832	1.2	NR	NR	-	-
106	Colonial Heights		3,427	5.1	1	1	-	1
107	Covington	20	1,658	2.5	1	0	1	1
108	Danville	97	7,691	11.5	3	1	-	3
109	Falls Church		1,097	1.6	NR	NR	-	-
135	Franklin City	44	1,806	2.7	0	0	-	0
110	Fredericksburg	59	2,204	3.3	NR	NR	-(3)	-
111	Galax	13	1,406	2.1	NR	NR	-	-
112	Hampton	574	23,883	35.8	36	17	-	36
113	Harrisonburg	31	2,363	3.5	NR	NR	-	-
114	Hopewell	47	4,652	7.0	NR	NR	—	—
137	Lexington		474	0.7	NR	NR	-	-
115	Lynchburg	394	10,220	15.3	NR	NR	-	-
143	Manassas City	142	3,369	5.1	0	0	-	0
144	Manassas Park	68	1,642	2.5	1	1	-	1
116	Martinsville	84	3,518	5.3	-	0	-	0

APPENDIX P (continued)

Public Schools City	(a) Sp.Ed.	(b) Total	(c) Projected Autistic	(d) Estimated Autistic-Like	(e) Identified Autistic	(f) Number Served	(g) Maximum Number
117 Newport News	352	26,123	39.2	-	0	3	3
118 Norfolk	1,565	37,489	56.2	NR	NR	-	-
119 Norton		1,028	1.5	NR	NR	-	-
120 Petersburg	335	7,718	11.6	NR	NR	-	-
142 Poquoson	10	2,275	3.4	2	0	2	2
121 Portsmouth	639	18,976	28.5	5	0	-	5
122 Radford	10	1,801	2.7	NR	NR	-(2)	-
123 Richmond City	2,027	31,531	47.3	4	0	-	4
124 Roanoke City	417	16,043	24.1	NR	NR	-	-
133 South Boston		844	1.3	**	**	-	-
126 Staunton	58	3,447	5.2	NR	NR	-	-
127 Suffolk	160	9,064	13.6	NR	NR	-	-
128 Virginia Beach	649	55,122	82.7	6	2	17	17
130 Waynesboro	29	2,952	4.4	NR	NR	-	-
131 Williamsburg	63	4,780	7.2	NR	NR	-	-
132 Winchester	101	3,234	4.9	NR	NR	2(1)	2
City Totals	8,834	338,500	507.8	73	25	29	89

APPENDIX P (continued)

Public Schools Town		(a) Sp.Ed.	(b) Total	(c) Projected Autistic	(d) Estimated Autistic-Like	(e) Identified Autistic	(f) Number Served	(g) Maximum Number
251	Cape Charles	5	208	0.3	*	*	-	-
202	Colonial Beach		563	0.8	NR	NR	-	-
203	Fries		467	0.7	NR	NR	-	-
207	West Point	41	738	1.1	***	***	-	-
Town Totals		46	1,976	3.0	0	0	0	0
State Totals		22,645	1,010,371	1515.6	150	49	114	217

(1) Regional program serving Frederick, Clarke and listed under Winchester City.
(2) Regional program serving Giles, Montgomery, Pulaski, Radford City and listed under Floyd (Ashtree).
(3) Regional program serving Caroline, King George, Spotsylvania, Fredericksburg City and listed under Stafford.
(a) Fall membership in Virginia Public Schools 1980-81 Department of Education - number of pupils in special education classes who are taught separately and for whom a separate register is kept.
(b) Fall membership in Virginia Public Schools 1980-81 Department of Education - Total school enrollment including special education (2).
(c) Based on an incidence rate of 15 per 10,000 students (Wing, 1979).
(d) Responses from local school divisions to the "Preliminary Information" form requesting the total number of students estimated with characteristics of autism. (NR - the form was not returned; - the form was returned indicating autistic-like are served but no numbers were given).
(e) Response from local school divisions to the "Preliminary Information" form requesting the total number of students specifically diagnosed with autism. (NR - the form was not returned; - the form was returned indicating autistic children are served but no numbers were given).
(f) Response from local school divisions to the "Descriptive Survey" listing number of individuals served with characteristics similar to those of autism.
(g) The greater number of (d), (e), and (f).

* Data listed for Accomack includes Northampton and town of Cape Charles.
** Data listed for Halifax County includes South Boston City.
*** Data for King William includes town of West Point.

APPENDIX Q

SURVEY OF INSTITUTIONS OF HIGHER EDUCATION

College/University	Response Received	Offers Course(s) in Autism	Offers Course(s) That Includes a Study of Autism	Does not Offer Any Study of Autism
Averett College				
Psychology Department				
Special Education	X		3	
Bluefield College				
Psychology Department				
Special Education	X		1	
Bridgewater College				
Psychology Department	X			X
Special Education	X		2	
Christopher Newport College				
Psychology Department				
Special Education	X			X
Clinch Valley College				
Psychology Department	X		1	
Special Education	X		1	
College of William & Mary				
Psychology Department	X		2	
Special Education	X		1	
Eastern Mennonite College				
Psychology Department	X		2	
Special Education	X		1	
Emory & Henry College				
Psychology Department				
Special Education	X			X
Ferrum College				
Psychology Department				
Special Education	X		3	
George Mason University				
Psychology Department				
Special Education	X		2	
Hampden-Sydney College				
Psychology Department	X		1	
Special Education				

APPENDIX Q (continued)

College/University	Response Received	Offers Course(s) in Autism	Offers Course(s) That Includes a Study of Autism	Does Not Offer Any Study of Autism
Hampton Institute				
Psychology Department				
Special Education				
Hollins College				
Psychology Department				
Special Education				
James Madison University				
Psychology Department	X		2	
Special Education	X		2	
Longwood College				
Psychology Department				
Special Education				
Lynchburg College				
Psychology Department				
Special Education	X		3	
Mary Baldwin College				
Psychology Department	X		1	
Special Education				
Mary Washington College				
Psychology Department	X		1	
Special Education	X			X
Marymount College				
Psychology Department				
Special Education				
Norfolk State College				
Psychology Department				
Special Education	X		1	
Old Dominion University				
Psychology Department	X		5	
Special Education	X			X
Radford University				
Psychology Department				
Special Education	X			X
Randolph-Macon College				
Psychology Department	X			X
Special Education	X		2	

APPENDIX Q (continued)

College/University	Response Received	Offers Course(s) in Autism	Offers Course(s) That Includes a Study of Autism	Does Not Offer Any Study of Autism
Randolph-Macon Woman's College				
Psychology Department	X			X
Special Education				
Richard Bland College				
Psychology Department				
Special Education	X			X
Roanoke College				
Psychology Department				X
Special Education				
Shenandoah College & Conservatory				
Psychology Department	X		1	
Special Education	X			X
Sweetbriar College				
Psychology Department				
Special Education				
University of Richmond				
Psychology Department				
Special Education	X			X
University of Virginia				
Psychology Department	X		3	
Special Education				
Virginia Commonwealth University				
Psychology Department				
Special Education	X			X
Virginia Military Institute				
Psychology Department	X			X
Special Education	X		1	
Virginia Polytechnic Institute				
Psychology Department	X		2	
Special Education	X			X
Virginia State University				
Psychology Department	X		3	
Special Education	X		1	

APPENDIX Q (continued)

College/University	Response Received	Offers Course(s) in Autism	Offers Course(s) That Includes a Study of Autism	Does Not Offer Any Study of Autism
Virginia Union University				
Psychology Department				
Special Education				
Virginia Wesleyan College				
Psychology Department				
Special Education	X		1	
Washington & Lee University				
Psychology Department	X			X
Special Education	X			No S.E. Dept.
Unidentified Responses	X X		2	X
Total % Responses	60.5%	0	53	18

APPENDIX R

EVALUATION OF SERVICE VARIABLES ACCORDING TO PRIORITY QUOTIENT

Service Variable	P.Q.*	Service Variable	P.Q.*
A.1. Policy/Procedure	1.24	E.2. Socialization	1.50X
2. Personnel	1.01	1. Play Skills	1.31
3. Coordination of Services	1.08	2. Peer Interaction	.89
4. Community Integration	.85	3. Interaction with authority	1.27
5. Program Evaluation	1.59X	4. Group interaction	1.35X
B.1. Annual Plan for Individual Clients	1.68O	5. Emotional Expression	1.62X
2. Short-Term Objectives	1.67X	6.	1.36X
C.1. Short-Term Objectives	1.88O	7. Use of community resources	1.75O
2. Service Environment	.87	8. Money management	1.31
3. Service Environment #2	1.61X	9. Use of public transportation	1.92O
4. Service Environment #3	1.62X	10. Sex Education	2.35O
D.1. Child Find	1.00	11. Planned experiences with non-handicapped individuals	1.68O
2. Diagnosis	1.86O	E.3. Personal Independent Skills	1.53X
3. Evaluation	.55	1. Grooming Skills	1.80O
E.1. Language Development	1.52X	2. Personal hygiene	1.72O
E.1.1. Language Training	1.19	3. Housekeeping	.58
2. Speech therapy	1.28	4.	
3. Sign Language	1.99O	5. Individual Living	
4. Total Communication	1.75O		
5. Other non-verbal communication systems	1.50O		

*P.Q. = Priority Quotient
O = + 1 S. D. (High priority)
X = 0 - 1 S. D. (Priority)

APPENDIX R (continued)

Service Variable		P.Q.*
E.4.	Pre-academic	.98
5.	Academic Instruction	1.16
1.	Reading	1.42X
2.	Language Arts	1.17
3.	Math	1.25
4.	Social Studies	.75
5.	Science	1.08
6.	Physical Education	1.27
E.6.	Specific Programming to Remediate Maladaptive Behaviors	1.44X
E.7.	Pre-vocational Instruction	1.22
E.8.	Vocational Instruction	1.45X
E.9.	Expressive Development	1.31
E.9.1.	Dance	1.16
2.	Music	1.02
3.	Art	.96
F.1.	Transportation	1.43
F.2.	Recreation	1.35X
F.3.	Counseling	1.24
F.4.	Psychotherapy	.99
F.5.	Physical or Occpuational therapy	.87
F.6.	Speech Pathology/ Language Training	1.47X
F.7.	Social Work	1.71O
F.8.	Audiological	1.54X
F.9.	Health-Medical	1.18
F.10.	Dental	1.75O
F.11.	Music, Dance Art Therapy	1.30
F.12.	Adaptive Physical Education	1.32
F.13.	Nutritional/Dietary Evaluation	1.47X
G.1.	Communication	1.30
G.2.	Training	1.57X
G.3.	Counseling	1.32
G.4.	Respite	1.80O
G.5.	Support	1.50X
G.6.	Advocacy	1.09
H.1.	Sheltered Employment	.94
H.2.	Supervised/Subsidized Employment	.72
H.3.	Vocational Rehabilitation	.93
I.1.	Adult Day Care	1.00
I.2.	Child Day Care	2.00O

*P.Q. = Priority Quotient
O = + 1 S. D. (High priority)
X = 0 - 1 S. D. (Priority)

APPENDIX R (continued)

	Service Variables	P.Q.*
I.3.	Transitional Living Arrangements	1.00
I.4.	Permanent Special Living Arrangement - Group home, Apt. living, specialized foster care	1.03
I.5.	Residential Children	1.51x
I.6.	Residential Adults	1.50x
I.7.	Leisure/Recreation Resources	1.53x
J.1.	Social/Legal/Informational Services	1.02
J.2.	Follow Along	1.00
J.3.	Information, Referral/ Locating Resources	1.17
J.4.	Consultation and Training	.86
J.5.	Follow-up	.95
	$\bar{x}$ =	1.33
	S. D. =	.35

*P.Q. = Priority Quotient
o = + 1 S. D. (High priority)
x = 0 - 1 S. D. (Priority)